

The Contradictions of Caregiving, Loss, and Grief during Emerging Adulthood:
An Autoethnography and Qualitative Content Analysis

by

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A Thesis Presented in Partial Fulfillment
of the Requirements for the Degree
Master of Arts

Approved November 2010 by the
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ARIZONA STATE UNIVERSITY

November 2010

ABSTRACT

Emerging adulthood—a developmental point in the life span (usually between the ages of 18-25) during which children no longer see themselves as adolescents but would not yet consider themselves adults—is marked by identity exploration and discovering new life directions. When emerging adults find themselves serving as caregivers for their parent during a time when they would normally be establishing autonomy and exploring new directions, they may feel conflicted by their desire to both care for their parent and maintain a sense of independence. Thus, using a multiple-method research design that includes both an autoethnography and a qualitative content analysis of young adult caregivers' online posts, this study intends to uncover the dialectical tensions (the interplay of communicative tensions within a relationship) an emerging adult daughter experiences in her relationship with her mother as she serves as her caregiver, experiences her death, and grieves her passing by analyzing the author's personal narrative. To provide a deeper understanding of the dialectical nature of the emerging adult caregiver experience, the study was extended with an examination of other young caregivers' experiences, drawn from online forums, to explore how they encounter tensions within their own relationships with their parents. An analysis of the personal narrative revealed one primary dialectical tension, separation-connection, and three interrelated tensions—predictability-change, openness-closedness, and holding on-letting go—that seemed to influence this primary tension. Results of the qualitative content analysis revealed that other caregivers experienced one primary dialectical tension, sacrifice-reward, and two

additional, interrelated tensions: independence-dependence and presence-absence.

A comparison of the findings from each methodological approach revealed both similarities and differences in experiences of emerging adult caregivers.

For my mother—a woman who lived beautifully and loved much.

ACKNOWLEDGMENTS

This thesis is a result of the commitment, care, knowledge, and invaluable support of many. First and foremost, I would like to extend my sincerest thanks to my incredible mentor and committee chair, Dr. Carla Fisher. Without you, I would have never been brave enough to actually process the loss of my mother. You encouraged me to face the most traumatic event of my life—and you were willing to face it right along with me. I am in awe of the work you do as a scholar and your willingness to dedicate so much time and energy to this project. You have shown me what it looks like to be an incredible teacher and an even better friend. I am so happy our lives crossed paths.

I am also incredibly grateful for the other members of my committee. I would like to thank Dr. Vincent Waldron who has always challenged me to go further and never failed to support me along the way. Had you not reached out to me after my mom died and encouraged me to return to the program, I am not sure I would have completed my degree. I am forever grateful for you. Thank you also to Dr. Douglas Kelley. It is difficult to express in words how much I appreciate you. You have taught me so much these past years, both in and outside the classroom. Thank you for your willingness to confront frightening things like cancer and death and for being my pseudo-therapist. It scares me to think about where I would be without you! Finally, I would like to thank Dr. Bianca Wolf for her wisdom and invaluable insight. I feel so fortunate to have had you—my authority on dialectical theory—as a committee member. Thank you for some very enlightening email exchanges.

I would also like to extend my deepest gratitude to the amazing faculty members in the Department of Communication Studies whom I have had the honor to work and think alongside during my time in the program. Dr. Ramsey Eric Ramsey, Dr. Lindsey Mean, and Dr. Jeffrey Kassing: thank you for your willingness to invest in your students. I have learned so much from you, and you have impacted my life in ways you may never have realized.

Lastly, I would like to thank my friends and family who have supported me throughout my journey. Thank you to my beloved communication comrades (you know who you are!), especially Carmen Goman, who studied, suffered, and rejoiced by my side these past two and a half years. And finally, to my husband Rane: I honestly believe I would never have survived the last few years of my life without you. Thank you for your love, your loyalty, and your beautiful, proof-reading eyes.

TABLE OF CONTENTS

CHAPTER	Page
1 INTRODUCTION	1
Informal Caregivers and the Family	3
Death/Loss	7
Death as a taboo topic	7
Death of a parent	8
Grief	9
Caregiving, Loss, and Grief during Emerging Adulthood.....	9
Contradictions of caregiving, loss, and grief during emerging adulthood.....	11
Caregiving, Loss, and Grief and the Mother-Daughter Relationship	12
The Dialectical Perspective.....	14
Bakhtin’s dialogism as a foundation for dialectical theory	15
A dialectical theory of relationships	16
Strategies for managing dialectical tensions	18
Dialectical tensions specific to the mother-daughter relationship .	19
Research Questions	21-22
2 METHODOLOGY	22
Crystallization: A Methodological Framework	23
Overcoming the art/science dichotomy	24
Credibility and rigor.....	27

CHAPTER	Page
Phase I- Autoethnography.....	29
Analytical process.....	31
Phase II- Qualitative Content Analysis.....	32
Procedures.....	35
Analytical process.....	38
Establishing trustworthiness	41
3 ANALYSIS AND FINDINGS	43
Phase I- Autoethnography.....	43
Personal narrative.....	43
Analysis.....	65
The contradiction of separation-connection	65
Caregiving.....	66
Loss.....	70
The contradiction of predictability-change.....	71
Caregiving.....	71
Loss.....	74
The contradiction of openness-closedness.....	74
Caregiving.....	75
Loss.....	77
The contradiction of holding on-letting go	78
Caregiving.....	79

CHAPTER	Page
Loss	80
Summary	82
Phase II- Qualitative Content Analysis	83
The contradiction of sacrifice-reward	83
The contradiction of independence-dependence	91
The contradiction of presence-absence	98
Summary	103
The Many Facets of the Crystal: A Comparison of Findings	104
4 DISCUSSION	108
Scientific and Theoretical Contributions to Family and Health	
Communication	109
Practical Implications	114
Limitations	117
Areas for Future Research	118
EPILOGUE	120
REFERENCES	127

Chapter One: Introduction

I am conscious of myself and become myself only while revealing myself for another, through another, and with the help of another.

-Mikhail Bakhtin

We understand death for the first time when he puts his hand upon one whom we love.

-Madame de Stael

My mother, the most selfless, genuine, and courageous person I have ever known, died of ovarian cancer on August 12, 2009. For more than two years, I served as my mother's primary caregiver, and although my mother and I were always close, serving as her caregiver created an intense bond between us, making her prolonged illness and recent death the most traumatic and devastating experience of my life.

I was only 21 years old when my mother was diagnosed with cancer (she was 50), and before then I never imagined living a life without her. Though I may not have always admitted it during my adolescence, I adored my mother and greatly depended on her my entire life. By the time I was 21, I was at a point in my life in which I had come to recognize and appreciate the countless sacrifices she had made for me over the years, and we were beginning to establish a deeper, more mature relationship. Like other *emerging adults*—those between the ages of 18 and 25 who no longer consider themselves adolescents nor see themselves as adults (Arnett, 2000)—maintaining an identity separate from my parents was important to me at the time; yet, I was still too young to imagine a life without a mother to take care of me. As such, I believe that when children lose a parent

when they are in their early twenties—a time when they no longer see themselves as independence-seeking adolescents but do not yet see themselves as autonomous adults who no longer “need” their parents—their experience of caregiving, loss, and grief may be radically different compared to adult children at later points in the life span.

To my knowledge, there is no existing research to date that examines the unique experiences of emerging adults as they serve as caregivers for a terminally-ill parent and adjust to inevitable loss. According to a meta-analysis of 629 caregiving studies, 48% of these studies focused on caregivers of dementia patients, 39% examined caregivers of demented and non-demented older adults, and 13% focused on caregivers of “physically frail” older adults (Pinquart & Sörensen, 2005). Because nearly all of the studies included in this meta-analysis centered on caregivers for older adults, it indicates that younger caregivers providing care for middle-aged parents are not well represented in extant caregiver literature. The lack of attention given to this population is striking, considering that many young adults and emerging adults serve as caregivers to loved ones—22% of all caregivers are between the ages 18 and 34 (National Alliance for Caregiving & AARP, 2009). Furthermore, there does not appear to be any research concerning the unique communicative experiences that emerging adults share with their parents during this time. Thus, using a multiple-method research design that includes both autoethnography and qualitative content analysis, I aim to uncover the communication dynamics of this unique family health experience. More specifically, I intend to uncover the dialectical tensions

(the interplay of communicative tensions within a relationship; e.g., separation and connection) an emerging adult daughter experiences in her relationship with her mother as she serves as her caregiver, experiences her death, and grieves her passing through an examination of my personal narrative. Additionally, I mean to gain a deeper understanding of the dialectical nature of the emerging adult caregiver experience by examining emerging adult caregivers' online postings that express tensions/contradictions within their own relationships with their parents.

In the following section, I review literature relevant to caregiving, death, grief, emerging adulthood, and the mother-daughter relationship in order to highlight how providing care for and experiencing the death of a parent can be an unexpected, contradictory, and complex experience for emerging adults—particularly, emerging adult daughters in the context of the mother-daughter relationship.

Informal Caregivers and the Family

Because the average caregiver in the U.S. is approximately 48 years old and female, much of the research reviewed below is reflective of this “typical” caregiver (National Alliance for Caregiving & AARP, 2009). Although the following literature provides us with keen insight into the experience of caregiving, it certainly leaves us to wonder about the unique experience of emerging adult caregivers, who may be impacted much differently given the vulnerability associated with their developmental point in the life span. Nevertheless, an understanding of the average caregiving experience is necessary

if we are to examine caregiving in the context of an ignored subpopulation, emerging adults.

Informal and family caregivers are terms that refer to unpaid persons who aid in patients' physical care and coping (Harrington, Lackey, & Gates, 1996). An estimated 65.7 million people in the U.S. served as unpaid family caregivers in 2009 (National Alliance for Caregiving & AARP, 2009). It is not surprising, then, that family is said to be the most likely source of day-to-day care for an ill loved one, and they play a vital role in the patient's recovery or adaptation to a long-term illness (Pecchioni, Thompson, & Anderson, 2006). Undoubtedly, the care and support of family members is invaluable to the well-being of many patients, as caregivers attend to both the physical and emotional needs of their loved ones (Pecchioni et al., 2006; Segrin & Flora, 2004). What is more, some studies have shown that caregiving can actually positively impact the caregiver as well as the patient, as it provides one with a sense of purpose, mastery, and increased emotional closeness to the ill family member (Donorfio & Sheehan, 2001). It appears that supportive communication and care from family members can potentially lessen the burden of being ill for patients (Segrin & Flora, 2004) and simultaneously positively impact the caregiver and their relationship.

Unfortunately, however, much of the existing literature on caregiving suggests that providing care for a family member can negatively affect both the patient and the caregiver. For example, Burles (2006) notes that mothers with breast cancer can have difficulty accepting care from family members because they do not want to "burden" loved ones with extra work and stress. Also, some

mothers and wives may feel conflicted if they simultaneously desire support from their families and attempt to maintain previous family roles.

Providing care and support to sick individuals requires time, energy, physical demands, and financial cost, which can lead to relational strain and emotional exhaustion for the caregiver (Pecchioni et al., 2006). Caregiving can also result in mental health risks for the care provider due to lack of sleep and social support, as well as anxiety about the patient's health, the future, and one's own health (Rabow, Hauser, & Adams, 2004). Similarly, a caregiver's perceived quality of life and symptoms of depression can be highly associated with that of the ill family member (Segrin, 2006). This may be especially true for those facing a potentially life-threatening illness such as cancer.

According to the National Cancer Institute (2010), there were an estimated 1,479,350 new cancer cases in the United States in 2009. Moreover, with the advent of new technology and treatment options, cancer care is often provided in outpatient facilities and in patients' homes (Miaskowski, Kragness, & Wallhagen, 1997). As a result, family members—in addition to managing the emotional, physical, and financial burdens that accompany a cancer diagnosis—often find themselves playing a significant role in providing care for patients and managing the (sometimes severe) side effects of treatments at home (Miakowski et al., 1997). As such, caring for loved ones with cancer can often result in both psychological and physical distress for the caregiver. One study suggests that the symptoms exhibited by women with breast cancer can, in fact, “spillover” to other family members (Segrin, Badger, Meek, Sieger, & Lopez, 2006). What is more,

the presence of pain in cancer patients can negatively affect the mood states of caregivers (specifically their level of anxiety and depression) and the negative impact on caregivers often increases as the stage of a loved one's cancer progresses (Miakowski et al., 1997). How caregivers and care recipients communicate with one another will inevitably affect the stressful experiences they encounter during caregiving. Their communicative behavior is a means of managing the challenges and stress of caregiving that affects both the care provider's and care receiver's well-being (Edwards, 2001).

To fully comprehend the complex and often stressful experience of caregiving, it is also important to recognize that neither cancer nor caregiving is a static event that occurs at a fixed point in time. Rather, cancer progresses (or includes multiple remissions and recurrences), and the caregiving experience progresses and fluctuates along with the trajectory of the disease. As Hoppes (2005) notes, caregiving often moves along a continuum from high to low intensity, and the nature of caregiving can move along this continuum in unexpected ways. As a result, a caregiver's experience early in the cancer trajectory may be much different than his or her later experiences. As mentioned above, caregiver burden, anxiety, and depression can increase when the loved one exhibits signs of pain or if the cancer metastasizes and progresses to a later or terminal stage. In fact, one study suggests that relatives of patients receiving palliative treatment (care that starts late in the disease trajectory, focused on mollifying painful symptoms rather than curing the disease) displayed the highest levels of anxiety, the greatest mood disturbances, and the poorest mental health

(Kurtz, Given, Kurtz, & Given, 1994). It seems, then, that caring for a family member once the disease has reached a terminal stage can be particularly distressing for the caregiver, as one is forced to contend with the idea of death.

Death/Loss

Upon learning of a terminal diagnosis, caregivers are confronted with the notion of impending loss and are often forced to contend with the inevitability of a loved one's death. Acknowledging the inevitable, however, is often incredibly difficult for both patients and their family members (Pecchioni et al., 2006).

Death as a taboo topic. In the U.S., conversations about death and loss are often avoided, and when one's prognosis is poor (e.g., a terminal illness such as metastatic cancer), doctors, patients, and patients' families may not acknowledge the impending loss (Pecchioni et al., 2006). Rando (1984) notes that the overall attitude in America is that death is antithetical to living and is an unnatural part of human existence; thus, many people go to great measures to protect themselves from the reality of death. However, protecting or shielding one another from death can cause family communication to "stiffen" and become restricted (Beach, 1995), and communication among family members can become less verbally explicit as an illness progresses (Pecchioni et al., 2006). These communication behaviors are often considered maladaptive, as avoiding conversations about death can negatively affect both the dying person's and his or her family members' ability to cope with loss (Pecchioni et al.). Perhaps more importantly, refraining from these discussions can contribute to a communication impasse between patients, family members, and healthcare providers, which may

“functionally block” opportunities for the patient to receive necessary palliative or hospice care (Lannamann, Harris, Bakos, & Baker, 2008).

Death of a parent. How one manages the notion of inevitable loss and how he or she copes with the actual loss of a loved one can vary depending on relationship type. According to Rosen (1986), “When a child’s mother or father dies...it is an event of unparalleled importance, of potential lifelong significance” (p. 2). Early parental loss, as may be experienced in emerging adulthood, is considered a tragic event and often evokes a search for explanation (Murray, Toth, & Clinkinbeard, 2000). Similarly, the death of a parent after a protracted illness like cancer can be particularly taxing, as the family has already experienced innumerable stressors during caregiving (Murray et al., 2000). Protracted illness also seems to be associated with difficulties in the physical, emotional, cognitive, and social functioning of those who are very close to the terminally-ill person (Rando, 1993). Although they are often not seen as such, deaths following a prolonged illness can still be perceived as “sudden” or “unexpected,” and one may have this perception if the death follows multiple cycles of relapse and improvement or if he or she is not yet ready to “let go” of the loved one (Murray et al., 2000). Because children, including emerging adult children, are often still dependent on their parents for comfort and support and may still see themselves as too young to lose their mother or father, it is quite possible that they would have a difficult time “letting go” of their terminally-ill parent. Thus, children at earlier points in the life span may perceive the death of

their parent as too sudden or unexpected, which may make the grieving process all the more difficult.

Grief. Grieving is a complex process, and the context of a loved one's death can affect the nature of this process (Pecchioni et al., 2006). Factors such as the age at which the loved one died, how he or she died, and the role he or she played in the survivor's life can all affect the grieving process (DeVries, 1997). Similarly, the centrality of the deceased's role in the family and the family's emotional dependence on the deceased can affect a family's adjustment to the loss (Shapiro, 2001). Losing a very close loved one is often extremely difficult, considering that the lost loved one may have previously served as the bereaved person's support system and is now no longer available to provide this support (Pecchioni et al., 2006). Because many emerging adults still depend on their parents for support and comfort, and considering they rarely expect to lose a parent at such a young age, it may be that grieving the death of a parent is an incredibly complicated and confusing experience for emerging adults.

Caregiving, Loss, and Grief during Emerging Adulthood

As discussed above, caregiving, death, and bereavement are hard to contend with, regardless of one's age. These life events, however, may be particularly challenging for emerging adults, considering that one usually "expects" these events to occur later in one's life, during older adulthood. Thus, serving as a caregiver and experiencing the death of a parent during emerging adulthood are considered *nonnormative* life events (see Nussbaum, 1989), and emerging adult children may find it particularly difficult to adjust to these

changes. As such, an emerging adult's experience of caregiving, loss, and grief may involve significant differences from that of the typical caregiver.

Emerging adults are thought to be more independent than children and adolescents, yet they do not share the same responsibilities as many older adults or young adults (Arnett, 2000). Emerging adulthood, then, is distinct from young adulthood not only because it spans a shorter age range ("emerging adult" usually refers to those between the ages of 18-25, while many consider young adulthood to begin at age 18 and last until one is 30 or older), but also because young adulthood implies that adulthood has been reached. This can be problematic because many of those referred to as "young adults" would not consider themselves adults. It seems more fitting, then, to describe these young people as gradually approaching or "emerging into" adulthood.

Because emerging adults are more independent than adolescents and also remain relatively free from adult responsibility, emerging adulthood is characterized by personal identity formation and the discovery of possible life directions, which often include "love, work, and worldviews" (Arnett, 2000, p. 469). Consequently, an emerging adult's relationship with his or her parents tends to evolve during this time because he or she usually desires autonomy during identity exploration (Arnett, 2000, 2001). Despite this desire for independence, however, European studies have shown that emerging adults continue to depend on their parents for support and comfort (Chisholm & Hurrelmann, 1995). Similarly, emerging adults in both the U.S. and Europe see "autonomy" and "relatedness" as complementary, rather than conflicting,

dimensions of their relationships with their parents (O'Connor, Allen, Bell, & Hauser, 1996).

Although emerging adulthood is distinct from adolescence—which is marked by a strong desire for independence from parents, a decrease in the time parents and children spend together, and a decline in parent-child relational closeness (Laursen & Collins, 2004)—emerging adults still desire independence and autonomy as they continue to explore their identities and future directions for their lives (Arnett, 2000). Considering that caregiving can lead to a loss of autonomy as one's other roles are neglected (Ellring, 1999), it is quite possible that emerging adults experience significant tensions when they serve as caregivers for parents, as they may simultaneously desire to both care for the person that they love and maintain their independence and autonomy.

Contradictions of caregiving, loss, and grief during emerging adulthood. Providing care for a sick parent, experiencing loss, and grieving a parent's death may be inherently challenging for emerging adults, as these children may see themselves (and may be seen by others) as old enough to serve as primary caregivers yet too young to experience the untimely death of a parent. As such, emerging adults may find themselves serving as primary caregivers during a time when they normally would be discovering their identity and pursuing new directions for their own lives. Emerging adults may feel conflicted as they adjust to the new roles and responsibilities of a primary caregiver during a time in their lives when they never expected to be caring for a sick or dying parent. It is quite likely they feel torn by their desire to both care for someone

they love so deeply and to maintain their autonomy or pursue new directions in their own lives. Similarly, because emerging adults are usually more dependent on their parents as compared to older adult children, the untimely death of a parent during emerging adulthood may leave emerging adult children conflicted as they must learn to “let go” of a parent despite the fact that they may feel that it is “too soon” or that they still “need” their parent. It is also possible that after the death of the parent, these former caregivers experience similar tensions during the grieving process as they attempt to adjust to life without a mother or father.

I believe there is a need for more research that focuses on emerging adults specifically, as this group is often ignored in the literature and their experience during and after caregiving is not clearly understood. What is more, considering that the most common caregiving dyad in Western society is a daughter caring for an ill mother (Miller-Day, 2004), it seems necessary to examine the experience of emerging adult daughters in particular.

Caregiving, Loss, and Grief and the Mother-Daughter Relationship

Compared to other caregiving dyads, emerging adult daughters caring for their mothers may experience caregiving in a very distinct way because the mother-daughter relationship is said to be the strongest and most enduring bond many women ever experience (Fischer, 1986). In fact, mothers and daughters are often said to live “linked lives” (Fischer, 1986). Fisher (2010a) discusses how daughters can share in the psychological, emotional, and even physiological changes that their mothers experience after a diagnosis of breast cancer. Indeed, some daughters of women with cancer diagnoses may actually experience

symptoms of posttraumatic stress disorder when their mothers experience emotional distress (Boyer et al., 2002).

As mentioned above, daughters frequently play key support roles for their ill mothers. Caregivers are predominately female, making up 66% of the caregiving population (National Alliance for Caregiving & AARP, 2009), and it may be that women often find themselves serving as caregivers because support and caregiving activities are usually seen as feminine in nature (Burles, 2006).

While serving as a caregiver for her mother, a daughter may assume the roles and responsibilities that once belonged to her mother, such as caring for younger siblings or maintaining the household (Burles). Adjusting to these changes may be difficult, especially for emerging adult daughters, as they not only experience changes in their identity (e.g., a daughter who now must act like a “mother”), but they must also manage the changes in their perceived autonomy and independence. Further, because of the intense emotional bond that a mother and daughter may share, it seems likely that losing a mother would be especially difficult for an emerging adult daughter. In fact, in her 2001 study about discussions of future caregiving in the aging mother-daughter relationship, Pecchioni found that nearly one third of the mother-daughter dyads she interviewed were in denial about the possibility of the mothers’ ailing physical condition. This suggests that these women did not or could not even think about the mothers’ declining health and its possible implications for their relationships, even in later life. The use of denial as a coping mechanism is suggestive of the stress and burden that mothers and daughters endure when they simply think

about the mothers' ailing health (Pecchioni, 2001), and it may also suggest the potential for a dangerous communication impasse. When one is in denial, the topic of death becomes taboo (see above), which can create an impasse that results in compromised end-of-life care for the mother. In light of this, it seems essential to examine how mothers and emerging adult daughters communicatively experience caregiving and loss.

Daughters may feel particularly conflicted when serving as a caregiver for their mothers, especially if this occurs early in the life span during emerging adulthood. Emerging adulthood is a time when a daughter is beginning to explore new directions for her life and establish autonomy from her mother; thus, serving as a caregiver for her mother—a role that usually comes much later in the life span—likely runs contrary to her expectations for her life and to the typical dynamics of the parent-child relationship. Therefore, when the mother-daughter role is reversed during caregiving, the relationship between the mother and daughter may become fraught with *dialectical tensions* (see below). It seems, then, dialectical theory is a fitting framework for examining communication in the mother-emerging adult daughter caregiving relationship.

The Dialectical Perspective

Previous research has shown dialectical theory to be a productive framework for examining some of the issues addressed in this current study. For example, scholars have used dialectical theory to examine the experiences of death and grief (e.g., Golish & Powell, 2003; Toller, 2005), the illness of a loved one (e.g., Baxter, Braithwaite, Golish, & Olsen, 2002), the mother-daughter

relationship (e.g., Miller, 1992; Miller-Day, 2004), and the mother-daughter relationship during health transitions (Fisher, 2010b). As one can see, dialectical theory offers scholars profound insight into the contradictions inherent in our communicative lives as experienced in specific relational contexts (e.g., mother-daughter bond) as well as significant life transitions (e.g., cancer diagnoses) and, as such, seems more than fitting for this study.

Bakhtin's dialogism as a foundation for dialectical theory. Dialectical theory is not a single, exclusive theory; rather, it is a family of theories centralized around certain assumptions and principles (Baxter & Montgomery, 1998). Baxter and Montgomery (1996) refined a theory of relational dialectics that originates from the work of the 20th century Russian philosopher Mikhail Bakhtin (Toller, 2005). Fundamental to Bakhtin's philosophy is his idea that consciousness—one's sense of self—is impossible without the other. It is interaction, or the relating between persons, that gives each consciousness meaning (Baxter, 2007). As Bakhtin explains:

[A] human being experiencing life in the category of his own *I* is incapable of gathering himself by himself into an outward whole that would be even relatively finished. ... In this sense, one can speak of a human being's absolute need for the other [in] producing his outwardly finished personality. The outward personality could not exist, if the other did not create it. (Baxter, 2007, p. 252)

Bakhtin goes on to explain that meaning is created alongside others within language and dialogue. His dialogic perspective suggests that one does not

simply “transmit” one’s attitudes, thoughts, and beliefs to the mind of a listener via communication; rather, we create and co-construct our social world, our sense of self, and our relationships through dialogue with the other (Baxter, 2007).

A dialectical theory of relationships. Following from Bakhtin, communication scholar Leslie Baxter sees dialogue as interactions that define and redefine relationships over time (Littlejohn & Foss, 2005). Relationships, therefore, are not something one works out cognitively in his or her head, but consist of conversations and interactions that occur over time. Baxter also suggests that relationships are dynamic, changing, and often manifest with dialectical tensions (contradictions) that are created and managed through communication. Thus, relationships, as created and defined through dialogue, are “the place where contradictions are managed” (Littlejohn & Foss, p.199).

At the core of relational dialectics is the concept of *contradiction*, or the dynamic tension between opposing forces that exist simultaneously (Baxter, 2006). This dynamic interplay of tensions—which are ever-present and on-going within relationships—are considered *both/and* rather than *either/or* (Baxter & Montgomery, 1997). In other words, although both poles of the tension mutually negate one another, they are also simultaneously interdependent; each depends on the other for its meaning (Arden Ford, Ray, & Hartmen, 1999). One should also recognize that these tensions are not seen as either “good” or “bad.” They simply exist (Pawlowski, 2006). However, it is important to remember that it is not the mere co-existence or co-presence of these relational tensions that make them significant; it is the interplay of these tensions and how they are constructed,

enacted, and managed through communication that make them meaningful (Baxter, 2006, 2011; Baxter & Montgomery, 1998).

A second assumption of dialectical theory is *totality* or interconnection. This generally refers to the interdependence of tensions—the idea that no single contradiction can exist in isolation of other contradictions and that they form an interdependent “knot” in which one contradiction may include, influence, or imply other contradictions (Baxter et al., 2002; Baxter & Montgomery, 1998; Werner & Baxter, 1994). More recently, Baxter has furthered this notion of interconnection, arguing that the application of relational dialectics theory benefits from a *contrapuntal analysis*, an analysis that focuses on the “interplay” of contrasting discourses (Baxter, 2011; Baxter & Braithwaite, 2010). Contrapuntal analysis is the methodological component of relational dialectics theory that encourages scholars to go beyond the mere identification of contradictions and begin to examine how the interplay of these tensions (how they relate to and enhance other discourses or compete with other discourses for centrality) ultimately creates meaning within relationships (Baxter, 2011; Harrigan & Braithwaite, 2010).

Along with interconnection, another important feature of totality is *situatedness*, which suggests the existence of contradictions that are indigenous to specific situations (Baxter et al., 2002). Although extant research surrounding relational dialectics points to three major families of contradictions within relationships (the dialectic of integration, the dialectic of certainty, and the dialectic of expression) totality—and more specifically situatedness—suggests

that these are not the only contradictions that exist within relationships (Baxter, 2006; Baxter & Montgomery, 1996). Different contradictions may be specific to other relational systems (Baxter, Braithwaite, Golish, & Olsen, 2002). Therefore, researchers are encouraged to uncover other contradictions in addition to integration, certainty, and expression that more precisely represent a unique communicative experience (Baxter, 2006).

Strategies for managing dialectical tensions. The ability to maintain a relationship often depends on individuals learning to manage the dialectical tensions experienced in the relationship, and scholars have moved toward investigating how individuals do so (Prentice, 2009). Baxter and Montgomery (1996) identify several potential strategies for managing dialectical tensions: spiraling inversion, segmentation, balance, integration, recalibration, disorientation, reaffirmation, and denial. In *spiraling inversion*, the dominance of one pole changes at different points in time and usually results in an irregular, spiraling shift between dominant poles throughout the relationship. Similarly in *segmentation*, the dominance of a particular pole changes, but it does so with the activity of the particular moment and is guided by its appropriateness in the specific context. *Balance*, on the other hand, is characterized by compromise or choosing a midway point between the poles by favoring neither one. *Integration* involves the simultaneous recognition of both poles, which can be achieved through ambiguous language and symbolic ritual. *Recalibration* refers to temporarily reframing or transcending the tensions so that they no longer seem oppositional but without altering their ongoing presence. *Disorientation* is

characterized by a “fatalistic attitude,” and the tension is viewed as inevitable and resistant to change (p. 62). Like disorientation, *reaffirmation* involves accepting that both poles cannot be reconciled; however, the tension is celebrated for the richness it affords and the meaning it brings to the relationship. Lastly, *denial* represents an attempt to overcome or avoid a tension by privileging one pole and denying the existence of the other.

Baxter and Montgomery (1996) propose that not all of the above management strategies are equally functional. Denying the existence of contradictions or viewing them as inevitable (disorientation) are strategies characterized by limited functionality. Accordingly, spiraling inversion, segmentation, balance, integration, recalibration, and reaffirmation are considered more functional strategies, as they embrace dialectical tensions in a way that denial and disorientation do not.

Dialectical tensions specific to the mother-daughter relationship. An emerging adult daughter and her mother may experience significant tensions during caregiving, as mothers and daughters have been found to experience multiple dialectical tensions across the life span of their relationship (Fisher, 2010b; Miller, 1992; Miller-Day, 2004). In her exploration of how mothers and daughters experience their relationship with one another, Miller (1994) found that the mother-daughter relationship is “manifest with contradictions,” and this includes the tension between independence and dependence (p. 14). Although a daughter’s desire for independence is often associated with adolescence, Miller notes that the dependence/independence contradiction is often evident in the adult

relationship as well. An adult daughter may search for her personal identity outside the family while “facing commonality and dependence in her relationship with her mother” (p. 14). Additionally, mothers and daughters experience several other contradictions in their relationship, including those between separation-connection, openness-closedness, real-ideal, and powerfulness-powerlessness (Miller-Day, 2004). Mothers and daughters can find themselves contending with such tensions and managing them communicatively, and often, life events can bring certain tensions to the fore. For example, Fisher (2010b) found that when a mother or daughter is diagnosed with breast cancer, the mother and daughter frequently express tensions between connection-autonomy and protection-expression when negotiating how to “be there” for one another.

The scholarship reviewed above indicates that dialectical tensions play a significant role in the mother-daughter relationship and that this theory can be a productive framework in understanding this bond. Furthermore, research demonstrates that dialectical theory is useful in examining health transitions related to the caregiving experience. For example, dialectical theory was used as a lens to explore the communicative experiences of hospice workers and how they managed the tension between “leading” and “following” patients and families in discussions of spirituality at the end of life (Considine & Miller, 2010). Also, dialectical theory helped illuminate the “married widowhood” experience of wives with husbands suffering from dementia, in particular how they negotiated tensions like past-present in their present communication with husbands who could not recall their shared past (Baxter, Braithwaite, Golish et al., 2002). What

is more, the experience of caregiving during emerging adulthood is likely manifest with dialectical contradictions, as this nonnormative life event often contradicts an emerging adult's expectations for his or her life and for the parent-child relationship. Considering this, the dialectical perspective seems to be an appropriate framework for an exploration of the contradictions/tensions that an emerging adult daughter and her terminally-ill mother experience in the specific context of caregiving, loss, and grief. Therefore, this study will attempt to address the following research question:

RQ 1: When an emerging adult daughter serves as caregiver for her terminally-ill mother, what dialectical tensions emerge across the caregiving trajectory through the transition to death and grieving?

It is also important to consider how these tensions are managed within the mother-daughter relationship. However, considering that there is much less dyadic/interpersonal communication (in the traditional sense) during and after the physical death of one of the relational partners, it seems more appropriate to examine how these tensions are mutually and communicatively managed during the caregiving process specifically. Thus, this study also intends to address the following research question:

RQ 2: How are these tensions managed communicatively during caregiving?

Because it is quite possible that other emerging adult caregivers experience significant contradictions—regardless of their gender or the gender of their parents—it seems important to examine the dialectical nature of other emerging adults' experiences while providing care for a parent. Doing so will

deepen our understanding of emerging adults' contradictory experiences as caregivers for their ill or dying parents. Therefore, this study will also attempt to address the following research questions:

RQ 3: What dialectical tensions do other emerging adult caregivers experience as they provide care for their parents?

RQ 4: How do emerging adult caregivers attempt to manage these tensions?

Chapter 2: Methodology

Family processes are inextricably linked to the passage of time, and as experiences and changes in the family gradually unfold, they influence and are influenced by communication (Nussbaum, 1989; Segrin, 2006). Therefore, investigations of these dynamic processes that occur over the life span call for more diverse methods of inquiry, methods that are more longitudinal in design and reflect this passage of time (Pecchioni, Wright, & Nussbaum, 2005; Segrin, 2006). Likewise, Baxter (2006) critiques current research for gathering data at one point in time and, thus, ignoring issues of change and flux. She advises researchers examining dialectics to undertake longitudinal studies that better capture these concepts.

Like family processes and dialectics, illness, too, is dynamic with milestones, transitions, and changing demands that unfold over time (Rolland, 1999). Likewise, the demands of caregiving are known to change as the disease itself changes or progresses. Grief is also conceptualized as a psychological and social/communicative *process* (Bosticco & Thompson, 2005). Therefore, it seems appropriate to not only examine family communication during caregiving and

grief collectively as a process but also to adopt a research method that can capture these experiences not as static points in time, but for what they are: dynamic processes that cannot be understood in isolation.

Crystallization: A Methodological Framework

In order to capture family communication, caregiving, and grief as processes, I felt it was best to examine these phenomena using multiple qualitative methods within an interpretive paradigm. Initially, this study consisted only of an autoethnography. Upon reflection, however, it seemed that in order to provide a fuller, richer description of the contradictions that emerging adults experience as they serve as caregivers for their parents, this study would be best served by examining the topic from multiple perspectives. Thus, I chose to employ two qualitative research methods—narrative autoethnography and qualitative content analysis (see below)—which serve to provide meaning from multiple positions. Although multi-method studies are becoming more common in the social sciences, studies that combine two or more epistemological perspectives (e.g., combining artistic/interpretive methodology with one that is more postpositivist/social constructionist) are more difficult to come by and are often misunderstood by other researchers (Ellingson, 2009). However, much to the delight of those who value the exploration of topics using qualitative methodologies from across the qualitative continuum, Ellingson, in her text *Engaging Crystallization in Qualitative Research* (2009), describes a methodological framework she calls *crystallization*. Unlike traditional mixed method studies that combine qualitative and quantitative approaches (see

Creswell & Plano Clark, 2007) or multi-method studies that blend multiple methods from the same tradition (e.g., qualitative methods), crystallization offers a sound argument for a researcher to combine two qualitative approaches from variant epistemological groundings. Adopting a crystallization framework for one's study requires that the researcher include at least one middle-to-right ground (e.g., constructionist, postpositivist) analytic approach and one interpretive, artistic, or creative analytic approach. In other words, he or she must give meaning to the data through more than one way of knowing (Ellingson, 2009). Crystallization allows researchers to not only combine different forms of data and analysis like traditional multi-method studies, but it also allows for the bringing together of “different genres and forms of sense making within interpretive methodology” that moves us past the “dualistic partitioning of qualitative methods into art and science” (pp. xii, 7).

Overcoming the art/science dichotomy. Ellingson (2009) suggests that there are many facets to the crystal—that is, there are many ways of seeing or understanding phenomena, and privileging certain epistemologies and methodologies over others can limit understanding. She proposes that

While artistic representations cannot fully capture the meaning of phenomena, neither can conventional reports. The tendency to romanticize traditional qualitative analysis as the primary and hence only authoritative account obscures its limitations as an inherently partial account embedded in relations of power. (p. 183)

The idealization of conventional reports and empirical evidence and the hesitation to embrace more artistic ways of knowing has a considerable history in the social sciences. In fact, this position can be traced all the way back to The Age of Enlightenment. A movement of thought that began in 18th century Europe, the Enlightenment is characterized by the idea of overcoming dogmatic traditions by way of rational thought and “universally reconstructable examination” (Honneth, 1987, p.699). Influenced by earlier philosophers such as Rene Descartes, Enlightenment thinkers emphasized the supremacy of scientific inquiry and rational thinking. The general belief was that one comes to know something in the world by way of empirical investigation, by “objectively” qualifying an object or phenomenon. Although this type of investigation can certainly lead to a better understanding of objects or phenomena (e.g., physical properties and characteristics, patterns of behavior, etc.), the danger lies in contemporary society’s propensity to conceive of scientific empiricism not as one way of knowing, but as the *only* way of knowing.

Recognizing that positivistic/scientific explanations are partial accounts of phenomena, the German philosopher Martin Heidegger in his highly influential text *Being and Time* (1927/1965) set out to show that scientific-empirical investigations can and do tell us valuable things about the world, yet they often miss what is most fundamental. Merely listing categorical descriptions, albeit useful in some ways, often covers over the “essence” of that which is under investigation. Heidegger says,

We shall not get a genuine knowledge of essences simply by the syncretistic activity of universal comparison and classification. Subjecting the manifold to tabulation does not ensure any actual understanding of what lies there before us as thus set in order. (p. 77)

Here, Heidegger explains that we cannot possibly uncover all there is to know about something by simply observing it “objectively” and listing its characteristics or physical properties. More importantly, we cannot fully understand human experience through quantitative measurements. As Heidegger reminds us, “The person is not a [t]hing, not a substance, not an object” (p. 73).

What we can take away from both Heidegger and Ellingson is that in order to gain a deeper understanding of human experience, we should adopt a methodology that accounts for more than one way of knowing or “seeing” the world. Humans are corporeal beings that cannot be fully understood using only scientific or empirical methodologies employed by an “objective,” disembodied researcher (Ellingson, 2005). Instead, scholars should remain open to methodologies that are reflective of lived experience (e.g., qualitative interviews, personal narratives) without dismissing them as “unempirical,” “groundless,” or “too subjective.” One should not forget that illness is certainly a lived experience, and research surrounding illness is well served by qualitative methodologies. Not only can qualitative investigations provide rich, descriptive, and personal data that a positivistic/scientific report may omit, but they may provide insight into how healthcare professionals can better provide “humane” care for their patients (Aull,

2010). Take, for example, a portion of the mission statement posted on New York University School of Medicine's "Medical Humanities" webpage:

The humanities and arts provide insight into the human condition, suffering, personhood, our responsibility to each other, and offer a historical perspective on medical practice. Attention to literature and the arts helps to develop and nurture skills of observation, analysis, empathy, and self-reflection—skills that are essential for humane medical care. (p.1)

As one can see, both scientific/empirical and qualitative/artistic methodologies have a place in social science and medicine; therefore, we should work toward viewing them as different ways of knowing rather than dichotomous or antagonistic modes of investigation. And researchers like Ellingson hope that crystallized texts that adopt methodologies from across the spectrum (from qualitative to quantitative but also within the continuum of qualitative approaches) will offer a way to permeate the boundary between the art/science dichotomy (Ellingson, 2009).

Credibility and rigor. One major facet of crystallization is the idea that knowledge is partial, constructed, and situated (Ellingson, 2009). Therefore, crystallization combines methods and genres in order to provide a broader understanding of a topic and to illustrate the limitations of knowledge. Each account (e.g., an autoethnography and qualitative content analysis) both complements the other by providing a new or alternative understanding and problematizes the other account by bringing its limitations and inherent partialness into relief. As Ellingson states:

Juxtaposing different ways of knowing through crystallization reveals subtleties in data that remain masked when researchers only use one genre to report findings. Thus, an emotionally evocative narrative points to the lack of human feeling captured in systematic data analysis, while analysis points to the larger social trends within which the unique, individual narrative must be situated to be understood. (p. 11)

Rather than lamenting the fact that nearly all accounts are inevitably partial and incomplete, crystallization allows one to appreciate them as additional viewpoints or “facets of the crystal” (p. 87).

Crystallization requires continual reflection of a scholar’s positionality in terms of data collection, analysis, and the representation of the researcher’s and participants’ identities. Because crystallization often problematizes and brings attention to differences in multiple accounts, it requires an acute awareness of one’s subjectivity. Thus, as Ellingson says, crystallization “offers far more rigor than *pretending* my subjectivity does not exist or has been somehow eliminated from the process of my research” (p. 184, italics in original).

As mentioned above, this study employs a multi-method design consisting of two methodological phases: Phase I, an autoethnography (personal narrative and analysis) and Phase II, a qualitative content analysis. Although each phase could exist as an autonomous study, presenting them together helps the reader recognize how the accounts relate and diverge, allowing him or her to draw personal or multiple meanings from the text (Ellingson, 2005) and deepening the

reader's understanding of this communicative experience. The methods used within each methodological phase of this study are discussed below.

Phase I- Autoethnography

The first phase of this study attempted to address the first and second research questions using the qualitative research method autoethnography.

Autoethnography is a postmodern form of ethnography that is usually written in first-person prose and combines ethnography with autobiography (Neville-Jan, 2003). Autoethnographers first gaze outward and focus on the broader social and cultural aspects of their personal experience before looking inward toward the self in a manner that is honest and resists cultural interpretations (Ellis & Bochner, 2003). As the autoethnographer looks inward and outward and back in again, distinctions between the cultural and personal become less clear (Ellis & Bochner, 2003), which not only provides insight into the personal experience, but also into the broader shared experience. As Ellis and Bochner (2003) put it:

I start with my personal life. I pay attention to my physical feelings, thoughts, and emotions. I use what I call systematic sociological introspection and emotional recall to try and understand an experience as a story. By exploring a particular life, I hope to understand a way of life. (p. 206)

In a *personal narrative* autoethnography (such as this study), the researcher assumes two identities: the academic self and the personal self (Ellis & Bochner, 2003). The researcher writes about his or her personal experience and then “makes sense” of or analyzes the story, often citing scholarly research. Not

surprisingly, the benefits of this introspection/self-expression and analysis are twofold. Bosticco and Thompson (2005) explain that

[Autoethnography] is likely to prove personally productive for scholars as it helps them cope and grieve themselves while enabling them to learn something about family communication and grieving for the benefit of other scholars and those in need. (p. 274)

Although therapy may not be the major objective in autoethnographic research, it is often the result of writing one's story well (Ellis & Bochner, 2003). This is not surprising considering many researchers discuss the benefits of storytelling and disclosure (e.g., Pennebaker, 2002; Sunwolf, Frey, & Keränen, 2005). Writing about traumatic experiences can improve one's health and well-being, and words can create structure to these traumatic experiences (Pennebaker, 2002). As stated earlier, the death of a parent is considered a tragic event that often evokes a search for explanation (Murray, et al., 2000). Considering that stories offer a way of remembering and understanding experiences and providing structure to confusing events—like the death of a parent—undertaking a personal narrative autoethnography seems very fitting for this particular study (Sunwolf, et al., 2005). What is more, autoethnography has shown to be an appropriate and productive way of examining the caregiving experience and providing insight into one's experience before, during, and after a family member's illness (see Alemán & Helfrich, 2010; Hoppes, 2005). Finally, it is important to mention the practical value of autoethnography, specifically illness stories, in regards to the practice of “narrative medicine” (see Charon, 2006). Narrative medicine enriches clinical

practice by incorporating personal narratives of patients into the practice of traditional medicine. Proponents of narrative medicine maintain that when physicians and nurses are made aware of and impacted by patients' lived experiences, they can offer more effective and empathetic care. Thus, this autoethnography holds value as an illness story that may offer insight into the lived experience of caregiving and oncology care.

Analytical process. In order to address Research Questions 1 and 2, I created a narrative of my personal experience as a primary caregiver and daughter of a woman with terminal cancer, focusing on the processes of caregiving, loss, and grief. After reflecting on my experience and creating an initial draft, I found that my experience could be best understood using the dialectical perspective as a guiding framework. Thus, the penultimate and final drafts of my narrative emphasized and highlighted contradictory experiences and how these dialectical tensions were managed in my communication with my mother. Although dialectical theory guided my narrative and analysis, it is important to note that my narrative was not written to "fit into" the theory. Instead, the theory was used as a framework, a way of making sense of my experience for myself and for my reader. Thus, I did not "choose" tensions to write about; rather, these tensions were brought into relief through the interconnected processes of critical self-reflection, narrative writing, and analysis.

As suggested above, artistic methodologies like personal narratives encourage readers to more directly draw personal and multiple meanings from the text, as compared to more traditional qualitative studies (Ellingson, 2009).

Therefore, it does not seem appropriate to use a traditional grounded theory analysis (a more postpositivist analytical approach) to examine my narrative. Because the personal sense-making involved in prewriting and writing is undoubtedly connected to how one analyzes and makes sense of his or her experience, it would be misleading to assume that my narrative is free from my positionality or that an analysis using grounded theory or the constant comparative method (see below) could produce “emergent” themes. Considering this, I found it more appropriate to write my narrative, step away from it for a week’s time, and then come back to read and reread with the intention of uncovering the dialectical tensions that were clearly present in the narrative. As mentioned above, a taxonomy of conventional dialectical tensions already exists; however, I did not intentionally attempt to reflect these tensions while writing my narrative. My analysis attempts to uncover the dialectical tensions that were present during my experience, whether I intended to highlight them during the writing process or not. Thus, the analysis identifies the dialectical tensions that seem to best illustrate and characterize my overall experience. Research is interwoven into my analysis in order to move my writing beyond my personal understanding into a broader cultural understanding/shared experience.

Phase II- Qualitative Content Analysis

The second phase of this study attempted to address Research Questions 3 and 4 and “points to the larger social trends” within which my personal narrative “must be situated to be understood” (Ellingson, 2009, p. 11). This phase, then, provides insight into the experiences of other emerging adult caregivers by

examining online discussion board and blog posts.¹ Originally, I had hoped to attend traditional face-to-face support groups for young-adult caregivers and listen specifically for the dialectical tensions that these caregivers may experience. However, I was surprised—and dismayed—to learn that very few caregiver support groups exist where I live (the fifth most populated city in the U.S.), and none exist for young-adult caregivers specifically. I was discouraged to learn that so few (if any) support groups are geared toward young-adult caregivers, and it confirmed my previously held position that young-adult—more specifically emerging adult—caregivers are often overlooked in research, resulting in fewer resources for their benefit.

This discovery, however, strengthened my resolve to learn more about the experiences of these caregivers, and I looked to other social forums that would grant me access to this understudied population. Considering that young adults are the most likely Americans to go online (93% of people ages 18-29 are Internet users), online blogs and discussion boards that center on the unique experiences of young-adult caregivers seemed like a viable option (Lenhart, Purcell, Smith, & Zickuhr, 2010). Upon a preliminary online search for young-adult caregiver resources, I was pleased to find quite a few forums that young adults had created to share their experiences and to connect/offer support to other young adults in similar situations.

¹ Throughout this section, I make reference to “young-adult caregivers.” This is because young adult is a “lay term” of sorts for emerging adult. That is, people are more familiar with the conception of young adulthood as compared to emerging adulthood and usually refer to themselves as young adults; thus, all online resources from which I gathered data were websites reserved for “young-adult caregivers.” However, in an attempt to capture the experience of emerging adult caregivers exclusively, posts from caregivers ages 30 and over were not included in this study (most online participants disclosed their ages in their posts).

It is not surprising that young adults would choose the Internet as a medium to connect with other caregivers. Not only are most young adults frequent Internet users, but as one blogger explained, young-adult caregivers often feel more comfortable in an online setting as compared to a face-to-face support group because they feel misunderstood by traditional support group attendees.

The blogger writes:

Support groups: I have been to many. I felt completely out of place.

Everyone in the room was generations older than [me]. While they stared at me with pity—they couldn't really relate to me either. Hence the online blogs and support forums—I found this a much better outlet for me. (5i)

Because traditional support groups created specifically for young-adult caregivers are so difficult to come by, it seems that an increasing number of young adults are turning to the Internet for social support. Although some researchers privilege more traditional “offline” ethnographic explorations over those conducted using the Internet, Garcia, Standlee, Bechkhoff and Cui (2009) suggest that a “virtual” site for research does not greatly differ from a traditional “real world” site. They argue that there is only one social world that contains both virtual and traditional sites of social interaction; therefore, it is imperative for researchers to include both traditional and online sites for studies as the distinction between “online” and “offline” worlds becomes ever more blurred in contemporary society. Although the authors encourage research that incorporate both online and offline realms, they also suggest that it may be appropriate for a researcher to “solely examine online behavior” when the members of the population under study have limited

contact with one another in traditional settings and when most (or all) of their contact is via computer-mediated communication (p. 55).

Statements from young-adult caregivers about their preference for online forums, coupled with the Internet's capability to afford access to such a specific population of caregivers, serve to justify my methodological decisions. And as Garcia et al. (2009) remind us,

To continue to effectively explore some of the main and enduring concerns of ethnographic research, ethnographers must incorporate the Internet and [computer-mediated communication] into their research to adequately understand social life in contemporary society. (p. 53)

Procedures. In an attempt to uncover some of the dialectical tensions other emerging adults experience during caregiving, I conducted a qualitative content analysis of blogs and discussion board posts written by young caregivers. Qualitative content analysis is one of the many research methods used to analyze a text. As opposed to quantitative content analysis, qualitative content analysis goes beyond simply counting words or phrases and carefully examines language for the purpose of organizing large amounts of text into an efficient number of meaningful categories (Weber, 1990). These categories can represent either explicit communication or inferred communication and serve to provide better insight into the phenomena under study (Hsieh & Shannon, 2005).

For this particular content analysis, I observed a total of five websites. These websites were selected because they were geared toward young-adult caregivers specifically, and each featured at least one discussion board or blog.

Each discussion board/blog included one (or more) initial post from a young-adult caregiver and several responses or comments to this post made from other caregivers. The posts and/or responses of approximately 70 caregivers were analyzed, which included 24 initial posts and 116 responses to these posts (approximately 77 pages of single-spaced text). During analysis, however, it was discovered that because these websites were geared toward “young caregivers” (a very broad age range), some of the participants were too old to be considered emerging adults, as they were 30 years old or over. Arnett (2000) notes that individuals may consider themselves emerging adults well into the late twenties, but by the time individuals are 30 or older, they usually view themselves as adults. Thus, anything posted by adults who were 30 years old or over was not used for this study. Additionally, it was discovered that other posts were made by those caring for someone other than a parent (usually a spouse). Because the aim of this study is to gain insight into the unique experiences of emerging adults caring for parents, these posts were not used. As a result, this study included the blogs/posts of 47 participants who ranged in age from 18-29 years, the average age being 22.5. Of these 42 participants, 32 were female, 9 were male, and 6 did not specify their gender. In terms of the gender of the parent, 26 participants noted caring for their mother, 9 for their father, and 12 did not indicate the parent’s gender. Lastly, 27 participants specified the illness of their parent. Of these, 7 parents had cancer, 6 had suffered a stroke, 3 were diagnosed with Parkinson’s disease, 3 had dementia, 2 had organ failure, 1 had suffered a traumatic brain injury, 1 had encephalitis, 1 suffered a heart attack resulting in

brain damage, 1 was diagnosed with multiple sclerosis, 1 had suffered a brain aneurysm, and 1 was a progressive quadriplegic. In order to ensure anonymity, none of the participants' real or online names were used. All names were replaced by participant numbers (1-47) and each of the participants' posts were labeled using a lowercase letter ("a" for the first post, "b" for the second, etc.)

Because the autoethnography portion of this study is very personal and highlights my own individual perspective, I chose to remain an "unobtrusive" observer rather than become a participant observer for this phase of the study (see Beaulieu, 2004). In other words, I did not directly interact with the bloggers, nor did I post anything on the blogs or discussion boards. It is important to note, however, that I did not choose to remain an unobtrusive observer because I wanted to uphold the positivistic notion of "objectivity." Although qualitative content analysis intends to present the perspectives of others and is less "subjective" than autoethnography, it would be fallacious for me to assume that my personal perceptions and worldview remain completely absent from my analysis and presentation of the data. Considering that the autoethnography presented my experience from my perspective, my intention for this phase of the study was to describe the experiences of other caregivers from *their* perspectives as authentically as possible, and I wanted to allow their experiences to "show themselves" to the reader. Thus, despite the inevitable existence of positionality, I attempted to let the experiences of the other emerging adult caregivers "emerge" from naturally-occurring, unobstructed data by employing the constant comparative method (see below).

Although it is true that I did not participate in the online interactions, I must note that I did post one time to each discussion board and blog. This onetime post asked for permission to use excerpts from caregivers' posts in my research. I chose to do this because the notion of "lurking"—observing and gathering data on the Internet undetected or withholding one's identity as a researcher—is a valid ethical concern for researchers conducting online ethnographies (Garcia et al., 2009). Thus, when I posted directly to the discussion board to ask for permission, I made my presence known to the participants and revealed my identity as both a former young-adult caregiver and a researcher. Each time I returned to the websites, I made certain to check any responses/comments to my post that would indicate that a participant would rather I not use any of his or her contributions to the site in my research. In several instances I was explicitly granted permission to use the content on the site in my study, and never did I see an indication that any participants were opposed to me using their posts or comments in my report.

Analytical process. The data analysis for this phase of this study was guided by grounded theory (Glaser & Strauss, 1967). Grounded theory is the attempt to draw conclusions or derive theory from an analysis of the patterns, recurrent categories, and themes that are found in observational data. Therefore, the constant comparative method (Strauss & Corbin, 1990) was used to identify emergent themes/dialectical tensions in the data.

Because scholars utilizing grounded theory can use *sensitizing concepts*—"suggestive ideas about what might be fruitful to examine"—(Clark, 1997, p.65)

to guide their investigations, I used dialectical tensions as a sensitizing concept during my analysis. It is important to note, however, that when examining the online data, I did not specifically look for the three conventional contradictions mentioned above nor did I look for the contradictions that were apparent in my own personal experience. That is, I did not have fixed dialectical tensions in mind and then set out to find examples in the data that “fit” these tensions. Although I was already aware of the tensions that were a part of my own caregiving experience, my intention was not to “prove” that others experience these same tensions or that they even experience dialectical tensions at all. However, when I endeavored to discover how emerging adults experience caregiving, it was obvious from my initial readings of the online posts that they did, in fact, experience tensions and attempted to manage them communicatively with their loved ones. Hence, I chose to use distinct references to feelings of tensions or contradictory feelings as the unit of analysis for my study. Specific references to tensions were determined by both manifest content (i.e., what the text actually “says”—specific keywords and phrases, such as “caregiving is a *sacrifice*” or “I’ve lost my *independence*”) and latent content (i.e., what the text is “talking about”—contextual cues that signified or implied tensions/contradictions; Graneheim & Lundman, 2004). Keeping my analytic focus open to any reference to tensions or contradictions allowed me to uncover new contradictions—contradictions that differ both from the conventional tensions already outlined in previous research and from those that I personally experienced during caregiving (see Baxter, 2006).

As recommended by Strauss and Corbin (1998), my analysis was an ongoing, continual process that began at the very start of data collection and ended when my reporting was complete. The process consisted of three steps. The first step involved reading the online posts and looking closely at individual references to tensions/contradictions. During this process, open coding was used to identify these tensions and their properties (Strauss & Corbin, 1990). This included identifying references to contradictions or tensions and labeling these references in the margins of the printed data. Step two of the analytical process involved the creation of categories (i.e., specific dialectical tensions). This included grouping the codes (specific tensions/contradictions) from the open coding process into higher order categories or “themes” (for this study “categories,” “themes,” and “dialectical tensions” are used interchangeably). A collection of concepts or codes can be considered a theme when the codes in that category show “thematic salience” (see Owen, 1984). According to Owen, thematic salience is indicated by *recurrence*—two or more posts that indicate the same meaning, although they may be worded differently; *repetition*—two or more posts referring to the same meaning using the same key words or phrases; or *forcefulness*—the underlining, boldfacing, italicizing, or capitalizing of whole words or phrases to show emphasis. Thus, references made to tensions or contradictions that recurred or were repeated by at least 25% of the participants (whether forceful or not) were considered thematically salient and grouped together under a common theme.

The third and final step of the analytical process involved developing and refining the themes/tensions by identifying each theme's properties and dimensions. After initially reading the data, noting clear references to tensions or contradictions, engaging in open coding, and combining codes to form themes, I returned to the data once again to uncover more tensions, and constant comparisons were made between all tensions. If themes/tensions emerged that did not fit into existing thematic categories, new categories were created. After identifying and categorizing all of the references to tensions in all of the data and creating an exhaustive list, the responses were read again in order to gain a deeper understanding of the themes and to determine whether any themes needed to be combined or further refined. This process continued until categorical saturation was achieved. Categorical saturation (saturation of themes/categories) is achieved when the examination of the data no longer offers new information—that is, gathering and examining more data would not serve to further explicate or refine what has already been discovered. Approximately two thirds of the way into my analysis, no new information emerged from the data. Although categorical saturation was achieved at this point, I chose to read over the remaining data to make certain that my themes were saturated and to look for any remaining exemplary quotations/excerpts from posts that could add richness to the description of my findings. Ensuring categorical saturation and providing rich descriptions serve to make one's research findings more trustworthy.

Establishing 'trustworthiness.' Graneheim and Lundman (2004) propose that research findings should be “trustworthy” and that trustworthiness should be

evaluated based on the procedures used to produce findings. Some scholars choose to use the same criterion for trustworthiness that are used in the quantitative tradition (validity, reliability, and generalizability); however, Graneheim and Lundman suggest applying concepts associated with the qualitative tradition when reporting findings of studies using qualitative content analysis. These concepts—credibility, dependability, and transferability—are interrelated and interconnected, although they are often discussed separately. I employed multiple verification strategies as outlined below to ensure my research design and findings were trustworthy (Morse, Barrett, Mayan, Olson, & Spiers, 2002). *Credibility*, which deals with the focus or intention of the research and how well the analysis addresses the focus, was ascertained by providing multiple participants' perspectives and including participants with a variety of caregiving experiences (as per Graneheim and Lundman, 2004). After the findings were written, I also went back to the data to compare the findings with the transcripts to ensure an accurate representation of the participants' voices. Furthermore, choosing a manageable, but not limiting, unit of analysis and providing quotations from participants to clarify categories also served to ensure credibility. I attempted to establish *dependability*, which refers to the researcher's ability to take into account the degree to which both the data and the researcher's methodological decisions change over the course of the analytical process, by taking detailed field notes throughout the analytical process and by analyzing throughout data collection. Each time I returned to the data, I began by reviewing my field notes to ensure that I remained immersed in the previously analyzed

data. The notes served as a reminder of the dialectical tensions that appeared to be emerging from the data and of any changes or concerns that I needed to address. Finally, *transferability* refers to the degree to which research findings can be transferred to other settings or populations. Graneheim and Lundman suggest that deciding whether or not the findings can be transferred to another context is ultimately the task of the reader; as such, I attempted to provide rich descriptions of the data using participant quotations in order to make my findings as transparent as possible for my reader.

Chapter 3: Analysis and Findings

Phase I- Autoethnography

The personal narrative that follows is an abbreviated but true account (true from my memory, perspective, and interpretation) of the past two and a half years of my life. The narrative should serve as a general frame of reference for my analysis, as my analysis will provide more detail and insight.

“I think my life began with waking up and loving my mother’s face.”

–George Eliot

Today is my 24th birthday. It’s been exactly 24 years since my mother, Joy, first held me in her arms, and it’s been exactly three months and 22 days since the last time she ever would. It’s ironic that I’ve chosen today—my first birthday without my mom—to share for the first time my experience of losing
5 her. I figure that today is going to be unbelievably painful no matter how I look at it, so I ought to harness that emotion and direct it toward something worthwhile.

On a Saturday in early May 2007, I took my mom out for breakfast. I wanted to have an important conversation with her, a conversation that I had been putting off for months. For years, my mom had been in a loveless marriage with my father, which was constantly leaving her feeling hurt, devalued, and lonely. So, after the waitress brought our food to the table, I took a deep breath and told my mother that part of the reason I had been distant lately was because it was hard for me to want to come home to a place where everyone was so desperately unhappy. I told her that watching her endure this life was killing me and that she had to get out of the marriage.

“I just want to do what’s best for you and your brother,” she explained.

“What we want the most, Mom, is for you to be happy. I just want you to be happy.”

I watched her cry over her French toast, and I held her hand when she finally agreed that she wanted more for her life and wanted to move out. We never expected that two days later she would be diagnosed with advanced ovarian cancer.

Our lives changed forever the moment my mom came home from work early to tell me that she received an urgent call from her physician. The doctor said that the results from a CAT scan she had ordered (my mom had been having dull abdominal pains for a few weeks) were “highly suggestive of advanced ovarian cancer.” The next few days were a whirlwind of tests and phone calls and

doctors appointments, all of which culminated in a definitive diagnosis and a date
30 for a tumor de-bulking surgery.

The waiting and uncertainty that come after a cancer diagnosis can only be described as agonizing. I was beyond terrified at this point, especially considering that everything we read on the Internet about ovarian cancer suggested it was a devastating and painful disease with a low survival rate.
35 Nevertheless, my mother remained positive and reassuring (as usual). She told her doctors to be very forthright, as she “wanted to know everything.” She said she wasn’t scared of the prognosis, and even told me at one point, “I’m not scared to die. I’ve lived a good life; if God wants to take me, He can.”

This is not what I wanted to hear, and it wasn’t long before the
40 inescapable thought of losing my mom took control of my life; I soon found it nearly impossible to leave her side. I wanted to share everything with her, accompany her to every doctor’s appointment, and I had a constant need to feel physically close to her—hug her, lay by her side, tell her how much I loved her and needed her. After her first surgery, I spent 12 days at the hospital with her,
45 sleeping on a cot next to her bed, eating cafeteria food, and only going home to shower.

My almost insatiable desire to be with my mom and the anxiety I experienced when I was away from her seemed strange to me at times. Only a few months before, I had been perfectly content to spend the majority of my time
50 with Rane (my boyfriend of several years) and my close friends. Although my mother and I had always had a healthy, loving relationship, there were times

during my adolescence and the beginning of emerging adulthood when I distanced myself from her in some ways, feeling that she had depended on me too much when things were difficult with my father. I so desperately wanted her to
55 live her own life, a life with which she was truly happy. I longed to feel that my mom simply wanted to spend time with me rather than needed to. Yet, even during those times when I distanced myself from her, I still remained enormously dependent on her in many ways. Anytime I was sick, I wanted her to take care of me, and when I was scared or anxious, she was the only one that I believed could
60 really comfort me. It was as if I wanted to “need” her, but I was overwhelmed when I felt that she needed me.

It wasn’t until a few weeks before her diagnosis that I started to reestablish the close relationship we had once shared (hence, the French toast breakfast). Now, as I spent sleepless nights in a cold, cramped hospital room, I felt intensely
65 guilty for not having pursued a closer and more mature relationship with her sooner. I couldn’t stifle the small voice in my head that repeatedly told me, “It took a cancer diagnosis to make things right with your mom, and you only want a relationship with her now because you’re afraid she’s dying.”

70 Upon returning from the hospital after that first surgery, I became my mother’s primary caregiver. This is something I absolutely wanted to do and felt comfortable doing. My new role probably seemed normal to others, as I was the only other female in our nuclear family. However, about six months prior to her diagnosis, I had made plans to study in England for the summer, and the date for

75 my departure was fast approaching. Immediately after my mother was diagnosed,
I had decided to cancel the trip entirely. There was no way I was going to leave
my mom, especially considering there was a 90 percent chance that I was going to
lose her in the next two to three years. How could I possibly go away for six
weeks when she needed me and when our time together was limited? It wasn't
80 long, though, before my mom sat me down for a chat.

“Nicki,” she said. “You still have to live your life. And I really want you
to go. At least go for a little while if you don't want to stay for the entire six
weeks.”

So, after further thought, some persuasion from friends and family, and a
85 tearful goodbye at gate C3, I got on a plane with my friend Carmen and tried to
make the most of my three weeks abroad.

Backpacking through Europe with my best friend was everything it was
supposed to be, with one exception: every time we laughed at our pathetic
attempts to communicate with locals or stood in awe of a Bernini or a
90 Michelangelo, I was overwhelmed with guilt. How could I be reveling in the
splendor of a vacation while my mom was at home suffering from the horrific
side effects of chemotherapy? The guilt and anxiety reached their apex when
Carmen received a call on her cell phone during our visit to Venice. It was my
boyfriend's mom (also my mom's close friend), Tracey, telling us that my mother
95 needed an emergency surgery to release an obstruction in her small bowel. At
that moment, in spite of all the fantastic things I had just experienced, I regretted
ever getting on the plane. I was angry at every person who had told me that

“getting away for awhile would be good for me,” and I wanted to fly home immediately. My mother, however, wouldn’t stand for it. She reminded me that
100 by the time I arrived, the surgery would be over anyway and that I should fly home when I had originally planned to.

An obscene amount of money spent on international calling cards was the only thing that got me through the rest of the trip.

When I returned home, I immediately resumed my role as caregiver. And
105 the feeling I had that I was the only one who could care for my mom “the right way” was intensified when she said quietly to me one day, “You know, when you were gone, your brother and your dad tried, but it wasn’t the same. ... I’m glad you’re back with me.” This comment, coupled with the guilt I felt for being in Europe during her surgery, made it impossible to even think of leaving her side.

110 For the next days, weeks, and months, I did everything I could for my mother, and irrationally refused help from anyone, despite many offers. I made her meals, did the laundry, drove her to chemo appointments, assisted her in the bathroom, and helped her shower when she was too weak. There were times she would become so sick from the chemotherapy—vomiting and trembling from the
115 pain—that I genuinely believed she was going to die. Because I was so afraid of losing her, I refused to leave her side, even sleeping next to her in her bed every night. And during these times, my mother never mentioned the importance of me “living my own life.” It was obvious that our relationship had clearly crossed the line between interdependency and codependency. Yet, it seemed like the least I
120 could do for the woman who had sacrificed so much for me over the years.

The summer progressed, my mom's body slowly began to heal from the surgeries, and her treatments became more tolerable. As a result, she could once again handle small tasks by herself. I was hesitant at first to let her do anything, but she said doing little things—washing dishes, making lunch, feeding the dogs—made her feel better, more independent. Before, when I was doing most everything around the house, she had apologized to me on several occasions for being “useless.” Though I reassured her she would never be useless to me or anyone else, I knew she would feel that way as long as I was “mothering” her. So, I stopped doing as much so that she could do more. Slowly, my mom began to feel stronger and stronger as she continued with her chemotherapy treatments. Until one day, in December 2007, we got the greatest news of our lives: my mother's cancer was in remission.

The next six months were beautiful. They were happy. They were normal. I could sleep in my own bed again and spend time with my friends, whom I had neglected for months. I no longer needed to spend every moment with my mother. I felt like I could pursue my own life, and I had plans to finally move out of my parents' house and into an apartment with some friends.

Not surprisingly, my mom discovered a new-found appreciation for life, and she too began pursuing new activities and new directions. She started exercising, eating healthy, traveling the country to visit friends and family, and

was preparing to return to her career as an RN case manager. She finally seemed genuinely happy with her life.

145 It was during this time that I really started treating my mother like a
“mom” again. I was once again the typical daughter who had no problem letting
her mother know when she was annoyed by something she’d said, one who no
longer felt guilty for being away from home for too long. Nevertheless, I was
surprised by the abrupt change in my mood at the mere mention of the word
150 “remission.” I knew that I loved my mother more than anything in the world, yet
I found myself having to make a conscious effort to spend quality time with her or
to tell her how much I appreciated her. It all felt so strange. I would think back
to how I felt before she was in remission, how I genuinely believed that I could
not function without being near her. Yet now it was so easy to pursue my own
155 interests because I no longer felt that sense of urgency, that feeling that our time
together was running out. Thus, it wasn’t long before I found myself busy with
school, busy with work and my friends and my boyfriend. But was I really too
busy for the woman who had just fought so hard for her life?

 I felt so conflicted. I understood I was no longer needed as a caregiver
160 and that some space was healthy and normal, but I could not understand why it
was so easy for me to express my desire for this space. When she was sick, my
desire to be near her had felt so natural; now, I found myself declining offers to
join her for a walk or to go see a movie. Yet the last thing I wanted was for my
mom to think that I felt justified treating her differently because she no longer had
165 cancer. Thus, I would intentionally replay images in my mind of the most

terrifying times of our past caregiving experience to remind myself how painful it would be to lose her and that I should appreciate every moment I had with her.

However, it wasn't long after I began to adjust to my new role as a non-caregiver that my mother received a call from her doctor. Her six-month routine
170 PET scan showed there had been a recurrence.

I could hear my mom on the phone with her physician, and instantly, all of the emotions from the previous year came screaming back. When she hung up, I came in the room and sat on her lap—something I hadn't done since the last time
175 she was sick.

“It’s come back? What does that mean? Can they get rid of it again?” I asked her in desperation.

“I’m not sure, Sweetie. All I know is that it is usually pretty aggressive when it’s a recurrence,” she replied.

180 I looked at her silently for a few moments, tears brimming in the corners of my eyes.

“Don’t worry,” she said. “It’ll be okay; God is in charge, and He will do what He wants.”

Her answer did not satisfy me in the least. “But what if He wants to take
185 you from me, Mom?! Please, please don’t leave me here, Mom, please!” I begged.

Later that evening, my mom asked me to take the dogs for a walk with her, and, of course, I obliged.

I watched my mom as she let our clumsy dog lead her, and I saw her smile
190 gently when she had to untangle his feet from the leash. My heart was broken. I
knew that she had to be afraid and tremendously disappointed.

“Mom, you know this doesn’t have to be a big deal. I say that we don’t
let it be a big deal. Let’s just not talk about cancer...only when we have to. When
we’re at the doctor’s, we’ll talk about it, but that’s it. When we’re at home, let’s
195 just go on like there’s nothing wrong. Can we do that?”

“Sure,” she said. “I guess we could do that.”

Shortly afterward, my mom began chemotherapy for the second time. I
quickly resumed my role as caregiver, but this time it was quite different. About
200 two weeks after the recurrence was discovered, my mom started having
debilitating headaches. An MRI was ordered, and we soon learned that what we
dreaded the most had happened: the cancer had metastasized to her brain and was
now incurable. My mother was terminally ill.

When the radiologist came into the waiting room to tell us that the MRI
205 showed metastases, I knew we could no longer pretend that it was “no big deal.”
I started to shake uncontrollably and felt sick to my stomach. My mom held me
as I cried on her shoulder and told her that I didn’t think I could do it anymore,
that I couldn’t handle the heartache, that I didn’t know how much more I could
take.

210 Very calmly and steadily, my mother looked down at me and said, “If you
need to, you can go away for a while. Someone else can take care of me. I don’t
want you to have to go through this.”

“No!” I cried. “Why would I leave you? I’m *not* leaving you.”

I couldn’t believe that my mom would say that. I couldn’t believe that
215 she could be so concerned for *me* when she had just received the worst news of
her life.

After learning of the metastases, I couldn’t escape the realization that my
time with my mom was running out. Because of this, my dependency on my
220 mother once again increased, and I again felt like I needed to spend every moment
with her. Even when she was feeling fairly well (which was the majority of the
time before she died), I could not help but feel an enormous sense of guilt when I
was not with her. I knew that my mother sensed this; she would constantly tell
me that it was good for me to get out, that I needed to spend time with other
225 people. Yet, when I would come home after doing so, she would say, “Hi,
Sweetie! I’m so glad you’re home. I missed you!” And whether she meant for
me to feel this way or not, I almost always took it to mean that she had been
lonely and I was gone too long.

Interestingly, despite our codependency, and despite the fact that I felt
230 guilty when I was not with my mother, there was a part of me that so badly
desired to live a “normal” life, like everyone else around me. All of my friends
were pursuing great things, buying homes, starting new careers, getting married—

and I was still at home. Yet, I *wanted* to be at home, and I didn't want to leave my mom alone. I guess what I really wanted was for my mom to be cured, so that we could both pursue what we wanted in life, and still be together. But since that was never going to happen, I was left feeling torn. No matter how many times my mom advised me, I did not know how to "still live my life" when I was losing the person who was most important to me. Even when Rane finally proposed to me after nearly seven years of dating, I could not feel genuinely happy. How could I be excited about the wonderful things that were happening in my life when my mother was losing hers?

During this time, however, my mother was faring relatively well. Therefore, it was easy for us to go about our lives as if everything was normal—though we had a new understanding of what "normal" meant. It had become normal for me to "mother" my mother, and it was normal for us to be around one another constantly. It seemed normal that I drove her around in her car and that our outings usually consisted of doctor appointments and ovarian cancer awareness meetings. The only time that life felt really "abnormal" was when we were confronted with the fact that my mother was actually sick. When she was forced to spend days in bed because of chemo-induced nausea and fatigue, or when it became difficult for her to do things like get out of the car or walk through a parking lot to the entrance of the grocery store, we were reminded of the reality of her disease. Nevertheless, we tried our best to push those abnormalities aside and considered them minor setbacks. When my mom was unable to join me for a party or dinner engagement, she was sure to remind me

that she would be okay and “back to her old self” in a day or two. And when she would ask for my assistance getting up or down a few stairs or in and out of the car, I often encouraged her to try it herself first. I thought that as long as she could keep pace with any physical changes, we could continue on as before. It
260 was as if we believed (or perhaps we were trying to convince one another) that we could keep the cancer under control if we maintained an appearance of normalcy.

It was in April 2009, about two months after Rane and I were engaged, that we saw the first signs that the cancer was progressing—and quickly. My
265 mom underwent surgery for another bowel obstruction, which resulted in a colostomy. For both of us, the colostomy was a tangible, undeniable indication of the devastation occurring within her body. Because I was aware of this, and aware that my time with my mother was limited, one might think that I was preparing myself for her inevitable death, but this was definitely not the case.
270 Although I cognitively understood that I was going to lose my mom, we both talked of her death as a far-off event that would *eventually* happen. We never talked about her dying, aside from her making vague statements such as, “Whatever God wants for me, I accept.” We would even discuss plans to visit out of state relatives in the coming months, despite the fact that we both knew her
275 chances of being well enough to do such things were very slim. Essentially, we were denying the fact that she was *actually* going to die. We tried one treatment after the next, hoping every time that this would be “the one” and never discussing what would happen if it wasn’t.

As the weeks and months passed, our doctors' visits became progressively
280 more terrifying, as blood work and scans showed further cancer growth. Still,
even through all of these terrible visits, the physicians never once mentioned that
we were at the end of the road in terms of treatment options, nor did they discuss
hospice care with us. And I never wanted them to. In fact, I had made it my
ultimate goal to protect my mom from the fact that she was dying. In an attempt
285 to prevent the physicians from giving us any kind of prognosis, I made sure to
attend all doctors' visits with her, despite the fact that I experienced such intense
anxiety at every appointment that it made me sick. I knew that if I was with her
in the exam room, my mom would not ask how long she had to live because,
ironically, she was trying to protect me from the same reality. Neither of us
290 wanted to hear the gravity of our situation, and, consequently, we never did.
When it came to prognoses, the doctors were always silent.

In June, the large tumor in my mom's abdomen began to bleed, and she
295 had to undergo three weeks of radiation therapy to stop the bleeding. She was
never the same after radiation. She grew incredibly weak and started to depend on
me much more to get through each day. I started to fear that she wouldn't make it
to the wedding that Rane and I had planned for November. I therefore moved the
date to October 3rd, telling my mom that the end of November would be "too cold
300 for a wedding," hoping that she wouldn't realize that I had moved it up to make
sure she'd live to see the ceremony.

I tried my best to take care of my mom at home for the rest of that month, fearing that any trip to the hospital would be our last. I could see her body changing dramatically, despite my best efforts to get her to eat and to help her
305 keep down what little food she did eat. Finally, my mom woke up on the morning of August 6th and said the words I knew would be coming soon: “It’s time to go to the hospital.” I had a feeling that this was going to be our final car ride together.

After she was admitted to the hospital, the doctors were strangely quiet. They said my mom had yet another bowel obstruction and that they would wait a
310 week to see if it would “resolve itself.” Despite my mom’s repeated attempts to learn how much the mass in her abdomen had grown, we never received an answer. My mom and I, because we so desperately wanted to cling to some sense of hope, took their silence to mean that she was going to be okay. You could imagine our surprise when three days into her hospital stay, they sent in a
315 palliative care doctor to discuss her “options.”

The palliative care physician suggested that my mother stop treatment and focus on “being comfortable.” My mom agreed with him, but when the doctor left the room she began to cry. She looked up at me, and choking on the words, said, “I have to face the fact that I’m dying.”

320 In desperation, I crawled into her bed, wrapped my arms around her neck, and told her that it didn’t mean she was dying, that it just meant she did not have to endure the pain of treatment. I tried to reassure her that everything was going to be okay and that it was all happening like it was supposed to. I reminded her of

what she had said about having lived a good life and being ready for whatever
325 God had planned for her.

I hated that doctor for telling my mom what I had been trying to keep from
her for so long.

Although I had told myself and others that I was prepared for the time
330 when hospice would become an option, I was not ready for it at all. So the next
morning, when my mother's doctor asked her if she'd like to start hospice care, I
was shocked. I couldn't believe he would suggest such a thing, when two days
ago, we were waiting for her bowels to heal so we could go home.

Her doctor explained to us that she wouldn't be "going to hospice to die"
335 but rather to live out the rest of her life comfortably, a life that no longer included
cancer treatments. As the doctor was leaving, to give my mom some time to
make a decision, Rane's mother, Tracey, came into the room. She had been in the
doorway and heard the conversation with the physician. Tracey had always been
such an incredible source of emotional support for my mom and me, and we were
340 relieved to see her. She could see the terror in both of our faces as she sat on the
edge of my mom's hospital bed.

"I know that was tough to hear," she said. "But I have been hoping and
praying for an opportunity to talk with you two, and I didn't know how to
approach it. I am so grateful that I came when I did."

345 I wanted her to stop talking. I wanted to pretend the doctor had never
come in and that we did not need to make any decisions about hospice. I wanted
everyone to stop telling my mom that she was dying.

“Joy,” Tracey said, “We can talk about this now...we really can face this
together. I truly believe that beautiful things can come at the end of life. And if
350 you accept it, you can enjoy the rest of your time with those whom you love; you
can tell them everything that you’ve wanted to. You can take time to think of the
bits of wisdom and truth you’ve uncovered during your life and want to pass on to
Nicki.”

My mom just listened, saying nothing.

355 “And the wedding!” Tracey continued. “You can be there! We’ll move it
to this coming weekend. I’m sure hospice will arrange it so you can be with
Nicki and Rane as they get married. Joy, this really *can* be a good thing. I know
it sounds so scary, but we can face this.”

My mother, the selfless woman, ever-concerned for her daughter, looked
360 at me and said, “I don’t know. ... Nick, what do you think?”

In our typical codependent fashion, I responded, “I don’t know, Mom. ...
It’s up to you.”

Before my mom could respond, Tracey interjected, “Joy, I know that you
want to do what’s best for Nicki, and I admire you for that. But this is your life;
365 this has to be your decision.”

When my mother decided to begin hospice care, she cried for all of a minute before she told me how incredibly content she felt with her decision. She said she was relieved she didn't have to "fight" anymore. As she made phone
370 calls to loved ones and excitedly made plans for the wedding, she seemed like a completely different person. Rather than avoiding the thought of her approaching death, she readily made plans for the care she would receive in her last days of life. I could not believe that the conversation I had dreaded most, the words that I thought would destroy my mother, had made her feel such a deep and profound
375 sense of peace. She spent the rest of that evening and the entire next day discussing wedding photographers and flower arrangements and caterers, all the while enjoying droves of visitors. My time was spent "excitedly" making wedding plans with my mom and quietly leaving the room when she had a visitor in order to cry in secret.

380 ***

No one, not even the physicians, expected my mother to die later that night. Relatively speaking, my mom was doing well the evening she died. She was up brushing her teeth and washing her face at the hospital sink before bed. I went up to the sink where she was standing, hugged her for a long time and said
385 between tears, "Mom, I just hope I loved you well enough before you got sick."

"Are you kidding me?!" she said. "I just hope I loved *you* well enough! You're the best daughter anyone could ever ask for."

We kissed one another before I got her settled into bed, helped her apply her face cream, and asked her if she'd like me to do her makeup for the wedding.

390 “I would absolutely love that,” she replied.

 The nurse then came in to give her some medication to help her sleep,
and we said goodnight.

 It was only an hour or so after the nurse left when I heard my mom’s
breathing begin to change and sound a bit gurgled. I knew this was not a good
395 sign, but I was in shock and disbelief that her body could start to fail so quickly,
considering that she was up and about just an hour before. Against the advice of
the nurses (who thought my mom would not die anytime soon), I immediately
called my family, my best friend Carmen, Rane, and his family. When they
finally arrived at the hospital, I was on the verge of an emotional and
400 psychological break down. My mom’s breathing was becoming more labored,
and she began to cough and she was confused as to why she was having trouble
breathing.

 I knew she was dying. I knew this was it. I started to visibly shake all
over my body, and I heard myself shouting, “It’s not supposed to be this way!
405 She’s scared! She knows something’s wrong! Someone, please help her!”

 I had never before felt so frightened or helpless. There was nothing I
could do. I couldn’t protect her from it. What we had both been denying for so
long was finally happening.

 Tracey was in the room with us. She grabbed my shoulders firmly and
410 told me to look at her.

“Nicki,” she said. “You have to calm down. Your mother needs you. If you’re scared, you’re going to scare her. You need to love her right now. You still need to take care of her.”

I stared at Tracey for a few moments, took some deep breaths, and
415 crawled into the bed next to my mom. I put my arms around her, and said in a shaky whisper, “I love you, Mommy.”

My mom was able put her arms around me as well, and she said, “I love you, too” for the last time. It was only then that I finally stopped shaking. Hearing those as her last words was the greatest gift I could ever ask for.

420 A few moments later, Tracey looked over at my mom. “Joy,” she said. “I’m still an ordained minister. Would you like me to marry Rane and Nicki, right now, right here next to you?”

She nodded yes.

My mother’s last conscious moments were spent watching Rane and I
425 exchange vows, as I promised Rane that I would choose to love him always, even when it’s difficult or felt impossible. I told my mom that the only reason I knew how to love Rane that way was because I had learned it from her. She had loved me so genuinely and so completely that it would take a lifetime to learn to truly love that way. But I made a promise to both her and Rane that I would spend the
430 rest of my life trying to do just that.

Five hours later, my mom began her final descent from this life, surrounded by her friends and family. The room was filled with people, and they softly sang to her and said their goodbyes. I cannot recall everything that

happened during that time, but I do know that I spent most of those five hours
435 lying next to my mom, with my head on her chest, listening to her heartbeat and
telling her how much I was going to miss her. I could not believe that I was
watching my mother die, but I felt comfort and peace as I rested in her arms, as if
she was comforting me during the most difficult time on my life. I told her that
even though I would give anything to have her stay with me, I was going to be
440 okay without her, and I was finally ready to let go. I thanked her for loving me so
well; I gently kissed her cheeks and touched her fingers, knowing that it would be
the last time I would be able to feel her warm skin. I so desperately wanted things
to be different, but I told her it was okay for her to leave me now.

With my head still on her chest, I listened to her beating heart—the same
445 steady sound that I must have heard as a tiny baby inside of her 24 years ago—as
it finally fell silent.

In the hours, days, and weeks after my mom died, I felt both intense
sadness and great relief. During the hours that my mother was dying, I remember
450 thinking how badly I wanted it to be over, how I wanted her body to let go. With
everything she had gone through, I knew that she had used every ounce of her
body and that it had nothing more to offer her. Thus, I was relieved when it was
finally over, and I was relieved that the relentless, paralyzing anxiety that I had
endured for several months had finally subsided. My mother was no longer in
455 pain, and I no longer dreaded the worst because the worst had already happened.

I no longer had to endure heart-wrenching doctor's appointments. I no longer had to "protect" my mom from the fact that she was dying.

Initially, I interpreted this feeling of "sad relief" as my way of grieving. I thought that perhaps since I had experienced anticipatory grief all through my
460 mom's illness that the process of grieving her death might be easier than I had ever expected it to be. And for the first few weeks, it *was* easier than I expected. I felt as if everything "made sense," that things had happened "the way God intended them to be."

But about a month later, my initial sense of relief started to wear off, and
465 reality began to set in. I missed my mother and developed an intense longing to be back with her. The thought of not being able to see her, and perhaps never seeing her again, was unbearable. Everything ceased to make sense. Yes, my mom was not in pain anymore, she was free from sickness and disease, but why did she have to have cancer in the first place? There were nights—there still *are*
470 nights—that were unbearable, where I could do nothing but cry in anger and confusion. Is it normal that I am holding on to such pain? That I cannot let go of the images of her dying? That I dread each day that passes, carrying me further away from the life I shared with her?

I do understand that there are things I must work through and "let go of"
475 in order to live a healthy life without my mother. But there are other things that I want to hold on to. Like the image of her huge, spirited smile or the sound of her moving around in the kitchen making a cup of tea every morning. Or the way she hugged people she had met only once. How she gave so much without expecting

anything in return. These are the things that made her who she was, that made her
480 the woman I admired and loved so profoundly. This is the Joy I will hold onto
always.

Analysis. Although the above narrative is an example of only one personal experience, we can use this narrative to uncover some of the dialectical tensions that may be present in the communication between mother and emerging adult daughter during the processes of caregiving, death/dying, and grief; how these tensions are managed; and the meaning they create within the relationship. Through the process of writing and reflecting on my own personal story, I was able to identify one primary dialectical tension, *separation-connection*, and three additional, interrelated tensions (*predictability-change*, *openness-closedness*, and *holding on-letting go*) that seemed to influence, and be influenced by, this primary tension. All four tensions are highly interrelated, and though discussed separately below, I highlight how each tension implies, influences, includes, and gives meaning to other tensions (as per contrapuntal analysis; Baxter, 2011). I examine each tension during the processes of both caregiving and loss and identify the strategies employed to manage these contradictions during the caregiving process. I begin with a discussion of the primary tension.

The contradiction of separation-connection. The dialectical tension of separation-connection, a part of the broader “dialectic of integration,” refers to discourses surrounding autonomy, independence, and separation on the one hand and discourses of (inter)dependence, connectedness, and integration on the other

(Baxter, 2006, p. 135). This primary tension was manifest and managed during my experience of caregiving and loss.

Caregiving. One of the most salient issues during caregiving is sustaining both autonomy and intimacy with a loved one in the face of impending loss (Rolland, 1999). It is likely that this tension is especially salient for an emerging adult, as issues of autonomy and identity are prominent in and of themselves during this phase of the life span. Unlike adolescents, who may distance themselves from a sick parent in “pseudo-autonomy” as an attempt to buffer the impact of loss (Rolland, 1999), young-adult (or emerging adult) daughters and their mothers may actually become more interdependent during their experience with cancer (Burles, 2006). Likewise, Rolland (1999) explains that an illness can push individual and family developmental processes towards increased cohesion, and this was definitely true for my mother and me. Like other emerging adult daughters, I spent my late teens and very early twenties establishing a sense of autonomy by “distancing myself from [my mother] in some ways” (line 52-53). Upon her cancer diagnosis, however, I instantly wanted to be close to my mother, and we became highly dependent on one another for emotional support, especially during the times that she was visibly sick: “I wanted to share everything with her ... I had a constant need to feel physically close to her ... [to] tell her how much I loved her” (lines 41-44). Likewise, my mother “never mentioned the importance of me ‘living my own life’” during the times she was most ill because she seemed to need me for care and comfort (lines 117-118). Eventually, our new connection and dependence on one another resulted in a dialectical tension as we confronted

both our emotional need for one another and our recognition that it was important to remain autonomous individuals.

My mother depended on me for care, comfort, and companionship; however, like other mothers who desire autonomy during their sickness and may feel guilty for being “a burden” (Burles, 2006), my mom still communicated her desire for independence. Despite the fact that there were times when she greatly depended on me to simply get her through the day, often “she said doing little things—washing dishes, making lunch, feeding the dogs—made her feel better, more independent” (lines 125-126). This tension was most evident when she would express that she felt “useless” when “I was doing most everything around the house” (line 126-128). Likewise, my personal autonomy and well-being as an individual also seemed to be an important issue for my mother. She expressed that she wanted me to “live my own life” during caregiving, and even encouraged me to take my trip to Europe, despite my fear and hesitation (lines 81-83).

Despite my mother’s apparent desire for healthy separation, her messages to me about maintaining a life outside of caring for her were often contradictory. She would tell me that she wanted me to spend time with others outside of the house, yet when I returned, she expressed how much she had “missed” me or how my “brother and dad tried [to take care of her], but it wasn’t the same” (lines 226, 107). To me, this implied that my mother *wanted* me to pursue a life outside of caregiving. Still, she seemed to be torn by her desire for the care and personal connection that she believed only I could provide. It was as if she cognitively and logically understood that our codependence was unhealthy; therefore, she said

what she was “supposed” to say. However, these messages were often negated by her expressions of need for me (e.g., lines 106-108). These contradictory messages may have been a result of managing the dialectical tension of separation-connection through *segmentation*—privileging either separation or connection at different times, depending on the appropriateness of the specific situation (Baxter, 2011). Thus, during the times that it seemed best to maintain a sense of independence (when she was feeling well, for example), her messages reflected this; during the times when she was very ill and needed me for care, comfort, or companionship, she expressed a desire for connection.

The contradiction concerning autonomy and dependence fluctuated along the trajectory of my mother’s disease. We continued to manage this tension through segmentation, depending on these disease changes (e.g., diagnosis, remission, and re-diagnosis). Before her diagnosis, I was only beginning to reestablish the close relationship that “we had once shared” during my early adolescence (line 63). After we learned she had cancer, however, I experienced an immediate and intense desire to be close to my mother, both physically and emotionally: “I found it nearly impossible to leave her side ... [I wanted] to hug her, lay by her side, tell her how much I loved her and needed her” (lines 41,43-44). My nonverbal behavior was similar to the findings of Fisher and Nussbaum (in press), which suggest that mothers and daughters show affection (e.g., kissing, hugging, hand holding) as a form of support and that this support often significantly increases immediately following a cancer diagnosis. Upon discovering my mother’s diagnosis, I experienced a desire for physical closeness

with her almost instantaneously. Any communication surrounding the discourse of autonomy disappeared, and I wanted to be as close to her as possible.

There were times, however, especially while her cancer was in remission, when I was easily able to express my need for autonomy and separation in our relationship. For instance, “I found myself declining offers to join her for a walk or to go see a movie” (lines 162-163; see also 145-148). Although my mother and I were still nonverbally affectionate during these times, I was less expressive of how much I needed her and depended on her. It was only during the times when my mother was not, or did not physically appear to be ill that I could make “plans to finally move out of my parents’ house” and pursue an independent life (lines 138-139). Although my mother was also pursuing new things in her own life—especially while she was in remission, as she “travel[ed] the country to visit friends and family, and prepar[ed] to return to her career” (lines 142-143)—it was “strange” to me that we were not as connected as we were during caregiving (line 152). Therefore, when I felt too disconnected or separated from my mother, I found myself “intentionally replay[ing] images in my mind of the most terrifying times of our past caregiving experience to remind myself how painful it would be to lose her” (lines 165-167). I also managed this tension through segmentation—in the moments that I felt too distant, I made “a conscious effort to spend quality time with her or tell her how much I appreciated her” (lines 151-152), despite the fact that I now found it “so easy to pursue my own interests because I no longer felt that sense of urgency, that feeling that time was running out” as I did during caregiving (lines 154-156).

Yet, as one might expect, this sense of disconnection and my desire for autonomy was again overcome by a sense of connection and my desire for closeness upon my mother's re-diagnosis. As soon as I resumed my role as caregiver—and especially when my mother seemed “sick”—I “again felt like I needed to spend every moment with her” (lines 220-221). My dependence on her only intensified as the disease progressed; I eventually started spending nearly every moment by my mother's side and constantly expressed to her how much I needed her—even begging her to not “leave me here” without her (line 185). At this point, we no longer managed the separation-connection tension by segmentation (fluctuating between the two poles, depending on how “sick” my mother seemed at the moment), as we had throughout the majority of the caregiving experience. Instead, we began to manage this tension through *denial*—choosing one pole and operating as if the other does not exist—and acknowledged/privileged only connection. Our communication reflected only our need for closeness, and the discourse surrounding independence and autonomy became non-existent within our relationship. As a result, in the moments that I thought my mother was going to die and when the disease reached its final stages, she and I seemed to lose sight of who we were as individuals. It became “obvious our relationship had clearly crossed the line between interdependency and codependency” (lines 118-119; see also 361-362).

Loss. Ironically, as my mother lay dying and I was forced to let her go, the separation-connection tension was still present. Although I verbally expressed to her that I was ready for her to leave me and that I would “be okay without her,” I

only felt at peace “as I rested in her arms, as if she was comforting me during the most difficult time on my life” (lines 437-438, 439-440). It was as if I needed to feel a connection with my mom, to have her hold me, to comfort me, and to help me through the most frightening moment of my life.

The contradiction of predictability-change. As suggested above, the tension between separation and connection was often related to the progression of my mother’s cancer and the resultant changes in her physical health and appearance. Traditionally, the contradiction of predictability-change is conceived of as the simultaneous desire for both certainty (stability, routine) and novelty (change, surprise) within a relationship (Baxter & Montgomery, 1996). Although my mother and I experienced both novelty and predictability within our relationship before her cancer diagnosis, our experience during caregiving and impending loss was marked by a fear of change—as change was an indication of disease progression—and I believed that “as long as [my mother] could keep pace with any physical changes, we could continue on as before. ... that we could keep the cancer under control if we maintained an appearance of normalcy” (lines 258-261). Thus, one can see that the predictability-change tension did not result from a desire for both predictability and change within our relationship; rather, this tension resulted from a desire to maintain predictability and routine in the face of ever-present, uncontrollable change.

Caregiving. Disease is a dynamic process with milestones, transitions, and changing demands that unfold over time (Rolland, 1999). As such, the experience of caregiving for a loved one with a disease is a dynamic process as well. As

Hoppes (2005) suggests, caregiving often moves along a continuum from high to low intensity and often in unexpected ways. Consequently, a caregiver's experience varies in intensity along the trajectory of the disease. What was most significant during my experience was not that my caregiving responsibilities fluctuated and changed as the disease manifested itself in different ways, but that the dialectical tensions my mother and I experienced were considerably influenced by disease-related changes. That is, when my mother was faring well and did not appear to be sick, "it was easy for us to go about our lives as if everything was normal" (lines 242-243). However, "when [my mother] was forced to spend days in bed because of chemo-induced nausea and fatigue, or when it became difficult for her to do things like get out of the car or walk through a parking lot to the entrance of the grocery store," we were reminded of the "reality of her disease" (lines 249-253). We were unable to accept this reality, however, and instead privileged both connection and predictability. Because our time together seemed limited when my mother appeared physically sick, we wanted to maintain an intense connection (as mentioned above), and, for me, acknowledging change and impending death was synonymous with acknowledging that we would ultimately lose this connection. Thus, we remained closed to adapting to change and "tried our best to push those [changes] aside and considered them minor setbacks" (lines 253-254).

Because change (physical change, change in treatment regimen, increase in frequency of doctor visits) was usually associated with disease progression, my mother and I attempted to keep life as predictable as possible by making

statements like “she would be okay and ‘back to her old self’ in a day or two” and repeatedly trying new treatments, “hoping every time that this would be ‘the one’ and never discussing what would happen if it wasn’t” (line 265, 277-278; see also 254-259). Similar to research findings that suggest caregiver burden, anxiety, and depression can increase when the loved one exhibits signs of pain or if the cancer metastasizes and progresses to a later stage, change often created a sense of anxiety and discomfort within our relationship (Miakowski et al., 1997). As a result, we attempted to manage the tension between change and predictability through *denial*—privileging predictability and refusing to acknowledge or adapt to change. For example, when my mother felt weak and asked “for my assistance getting up or down a few stairs or in and out of the car, I often encouraged her to try it herself first” (lines 256-258). How one maintains a sense of “control” over one’s cancer has received much attention in scholarship across multiple disciplines (e.g., Osowiecki & Compas, 1998; Goldsmith, 2004). As shown above, my mother and I attempted to “control” her cancer by refusing to adapt to change because change was an indication of cancer growth. Accordingly, we attempted to create the semblance that things were “normal.” We said these things in an attempt to control the chaos that was all around us, as a way to protect ourselves from reality. When things seemed out of control, our immediate reaction was to maintain normalcy and routine, hence, my desperate attempt to keep things under control by suggesting that we not make them into “a big deal” and to “not talk about cancer” (lines 192-193).

Loss. Near the end of my caregiving experience, the cancer's progression and the inevitable changes that accompanied this progression became more and more difficult to control. It was incredibly difficult to maintain a sense of normality when "I could see [my mother's] body changing dramatically, despite my best efforts to get her to eat and to help her keep down what little food she did eat" (lines 303-305). And it soon became clear that my mother needed to be taken to the hospital. It was then that I knew the cancer had won, that I could no longer stave off the changes and ignore the inescapable. However, as I began to surrender all attempts to "control" my mother's illness, I still did not want to talk to my mom about her approaching death. I focused my efforts on protecting my mother from the reality that the cancer had prevailed, and I desperately "wanted to pretend the doctor had never come in and that we did not need to make any decisions about hospice. ...I wanted everyone to stop telling my mom that she was dying" (lines 345-347). This notion of being closed off toward conversations about my mother's inevitable death is further explicated in the following tension.

The contradiction of openness-closedness. This tension refers to the contradiction between our willingness to openly discuss the topic of death and our tendency to protect one another from the reality of death by remaining closed to this topic. During the times that I desired closeness and connection with my mother, I became very open with her and "wanted to share everything with her" (line 41). Yet, despite our openness with one another, as her cancer progressed, there was one topic that we desperately tried to avoid: that she was dying. Eventually, our communication about her death changed from a simple avoidance

of the topic to a strict and deliberate closedness toward it, as I had “made it my ultimate goal to protect my mom from the fact that she was dying” (lines 283-284; see also 285-291). This dialectical tension between openness and closedness was most manifest during the final stages of her illness when our time together seemed most limited.

Caregiving. Interestingly, when my mom was first diagnosed with cancer, we were relatively open about the topic of death. My mother even told me at one point, “I’m not scared to die. I’ve lived a good life; if God wants to take me, He can” (lines 37-38). Yet, after her re-diagnosis and when the disease started to quickly progress, these kinds of statements became less and less frequent. As death became less like a far-off event and more like something that could actually happen, both my mom and I remained closed to any conversations about her prognosis and “never talked about her dying, aside from her making vague statements such as, ‘Whatever God wants for me, I accept’” (lines 271-273; see also 275-278; 289-290).

Similar to the mothers and daughters in Pecchioni’s (2001) study, it is very likely that both my mother and I used denial as a coping mechanism throughout the caregiving experience. It was much easier for us to avoid discussions of death and pretend it was not happening than to face the fact that we were going to forever lose the person we loved so much. Much like families whose communication “stiffens” when members attempt to shield each other from the subject of death (Beach, 1995), as time progressed and death loomed closer, the communication between my mother and me shifted from openness about

death and loss to extreme closedness surrounding the topic. I soon developed an intense desire to shield my mom from any kind of end-of-life conversation in order to “protect [her] from the fact that she was dying” (line 284).

It is apparent that my mother and I also used *denial* as a management strategy for the dialectical tension of openness-closedness. Using denial as a means of managing dialectical tensions is different than “denial” as discussed above (i.e., denying the fact that my mother was dying; denial as a “coping mechanism”). Instead, it refers to the idea that my mother and I were denying the possibility for openness toward discussions of death, therefore limiting our communication about this topic. However, it is interesting how this management strategy actually served as a coping mechanism in our relationship. Denying the existence of the pole of openness toward death (a management strategy for dialectical tensions) contributed to our denial of her inevitable death (a coping mechanism).

Denial is considered a dysfunctional management strategy because it has “limited functionality” for managing tensions (Baxter & Montgomery, 1996, p. 61). What is more, denying openness and privileging closedness toward conversations about death contributed to the communication impasse that occurred between my mother, myself, and her healthcare professionals (e.g., “Despite my mom’s repeated attempts to learn how much the mass in her abdomen had grown, we never received an answer. My mom and I, because we so desperately wanted to cling to some sense of hope, took their silence to mean that she was going to be okay,” lines 310-313; see also 287-291). When the

prognosis of an illness is poor—as was my mother’s—physicians, patients, and family members may not discuss the inevitable (Pecchioni et al., 2006). Even though patients may say that they want to talk about issues such as death and dying, when it comes to actual crises, they avoid the subject in practice (Lannamann et al., 2008). Despite the fact that my mom had told her doctors in the very beginning that she wanted “to know everything,” as the cancer progressed, “neither of us wanted to hear the gravity of our situation, and, consequently, we never did. ... When it came to prognoses, the doctors were always silent” (lines 35-36, 289-291). The physicians simply suggested new treatment options, and we gladly “tried one treatment after the next, hoping every time that this would be ‘the one’” (lines 276-278). Research has shown that chemotherapy may have an anxiety-reducing effect, as patients feel that they are “actively fighting” the cancer (Edwards & Clarke, 2004). In our case, we futilely tried one treatment after the next, despite the fact that we essentially anticipated their ineffectiveness. Doing so contributed to the sense we were “fighting.” It allowed us to avoid discussions about death because, to us, she was not dying as long as we were still fighting.

Loss. Family-led end-of-life discussions that occur early in the disease process can improve quality of life for both patients and their families; yet, these conversations often do not occur until all other options have been exhausted (Lannamann et al., 2008). In my mother’s case, this conversation did not occur until the day before she died, and our closed communication surrounding death and loss likely contributed to the significant delay of its initiation. As a result, my

mother and I were significantly unprepared for our conversation with the palliative care physician, and “when my mother’s doctor asked her if she’d like to start hospice care, I was shocked. ...I couldn’t believe he would suggest such a thing, when two days ago, we were waiting for her bowels to heal so we could go home” (lines 331-333). However, once my mother finally decided to begin hospice care, she told me “how incredibly content she felt with her decision,” that “she was relieved she didn’t have to ‘fight’ anymore” (lines 368-369). It was as if my mother no longer had to protect me from the fact that she was dying because it had finally been openly acknowledged and articulated. She was finally open to end-of-life conversations, and “rather than avoiding the thought of her approaching death, she readily made plans for the care she would receive in her last days of life” (lines 371-373). It is unfortunate, however, that this did not occur until the day before she died.

The contradiction of holding on-letting go. Denying the fact that my mother was dying and remaining closed-off to conversations about death allowed us to hold on to the belief that my mother was not *actually* going to die anytime soon. Thus, we never made any steps toward letting go of our relationship or our attempts to control her disease until we were forced to do so. This tension between holding on and letting go was present throughout my entire experience of caregiving and loss. Although the tension of holding on-letting go sounds very similar to the tension of separation-connection, this tension is nuanced by the notion of impending death. Unlike separation-connection, a tension that my mother and I experienced throughout our relationship even before her diagnosis,

the tension between holding on-letting go is framed by the realization of permanent separation from one another.

Caregiving. Rolland (1999) suggests that families can better handle the process of caregiving for a member with a terminal illness when they shift their focus from controlling the disease to “letting go,” which includes acknowledging the impending loss. Not surprisingly, denying that my mother was dying and closing ourselves off from necessary end-of-life conversations made the process of letting go exponentially more difficult. All throughout caregiving and up until the days before my mother’s death, “we were denying the fact that she was *actually* going to die” and focused on fighting and controlling the disease (lines 275-276). We held on to the hope that her treatments would be successful, and our communication reflected this hope. We discussed things like “visit[ing] out of state relatives in the coming months, despite the fact that we both knew her chances of being well enough to do such things were very slim” (lines 273-275). As discussed above, even though we cognitively understood that we would one day be forced to let go of each other, we desperately held on to our attempts to control the disease and our hope for a cure (see lines 259-260; 276-278). Similar to the dialectical tensions previously mentioned, we often managed the tension of holding on-letting through *denial* during the caregiving experience. As her condition worsened, we invariably stopped saying anything that might indicate the possibility of letting go; we refused to talk about what would happen if and when she died and ultimately privileged communication that allowed us to hold on to hope (e.g., “We both talked of her death as a far-off event that would

eventually happen. ... We never talked about her dying,” lines 270-271; “Essentially, we were denying the fact that she was *actually* going to die. ... We tried one treatment after the next” lines 275-278; “I knew that if I was with her in the exam room, my mom would not ask how long she had to live,” lines 287-288; “My mom and I, because we so desperately wanted to cling to some sense of hope, took their silence to mean that she was going to be okay,” lines 312-313).

It is quite apparent that all of the tensions manifest in our communication during the caregiving experience contributed both to the communication impasse that occurred and the difficulties we faced in terms of “letting go.” As my mother’s disease progressed and she showed signs of an impending death, we became increasingly more connected and dependent on one another for comfort and for reassurance that everything was “going to be okay.” As such, we attempted to protect one another from the reality of inevitable loss and closed ourselves off from any discussions about this loss. We held on to the hope that she would not die if we kept fighting, and we were unable to let go of our attempts to control the disease. Consequently, we were unprepared for end-of-life discussions surrounding my mother’s inevitable death, which made the process of actually letting my mother go (experiencing her death) incredibly painful and difficult for me.

Loss. Having been unprepared for discussing my mom’s impending death, the decision to start hospice care dramatically intensified the tension I felt between holding on and letting go. When my mother decided to begin hospice care, and it was clear that she really was going to die, we were essentially forced

to face the reality of letting go. However, despite the fact that we were finally open to discussing her death, I continued to feel conflicted about letting go, and my last day with my mother was “spent ‘excitedly’ making wedding plans with my mom and quietly leaving the room when she had a visitor in order to cry in secret” (lines 377-379). How was I to let my mother go when she was still alive? Pecchioni et al. (2006) propose that when one faces the impending death of a loved one, he or she must remain physically and emotionally available to the loved one while simultaneously understanding and discussing with others what the future will be like without this loved one. Similar to this idea, in the hours before my mother began to die, I felt like two different people: when I stepped foot inside my mother’s hospital room, I was a daughter who was “excited” about having her mother at her upcoming wedding, and when I stepped out, I was a daughter who was mourning the approaching death of her mother and attempting to let go of her forever.

When death did approach, and as my mother lay dying, I was surprised by “how badly I wanted it to be over, how I wanted her body to let go,” despite the fact that I could not let go myself (lines 449-450). However, I also wanted to remain connected to her at the same time; I needed her to “comfort me during the most difficult time on my life” (line 438). Somehow, I wanted so badly for her to die quickly—even telling her “it was okay to leave me”—even though “I so desperately wanted things to be different” (lines 442-443). These contradictory feelings may have contributed to the strange sense “of both intense sadness and great relief” I felt upon her death, and they may also clarify why “my initial sense

of relief started to wear off’ a few weeks later: I wanted to let go of my mother’s weak, wounded body, but never did I want to let go of my mother (lines 248-249, 464; see also 450-454; 480-481).

Summary. The dialectical tensions discussed above are not significant for their mere co-presence but for how their interplay created meaning within the mother-daughter relationship (Baxter, 2011). Thus, it was not my intention to show how my mother and I sometimes experienced connection and sometimes autonomy, or that caregiving became more unpredictable as her disease progressed, or how conflicted I felt about letting her go. My intent, rather, was to illustrate how all of these tensions worked in concert to create a much greater, more complex relational dynamic. The dialectical tensions my mother and I experienced influenced each other in such a way that—despite the fact that I was able to separate myself from my mother and pursue directions in my own life when my mother appeared to be well—as her disease progressed and became increasingly more difficult for us to predict or “control,” our codependence intensified. As a result, we completely closed ourselves to conversations about her death, making it much harder to let go. Ultimately, our codependence and closedness toward discussions surrounding death contributed to the communication impasse that occurred within the mother-daughter relationship and between us and her physicians.

The primary tension of separation-connection remained at the fore of our relationship throughout our experience. From the moment of my mother’s diagnosis until the moment she died, we constantly struggled to maintain a

normal, healthy sense of autonomy and dependence. We rarely felt that we achieved this, partly because our entire experience—coping with a cancer diagnosis, reversing mother-daughter roles, contending with death early in the life span—felt so entirely abnormal. Because serving as a caregiver during emerging adulthood is an unexpected, “abnormal” life event, and because emerging adulthood is a time already marked by issues of autonomy and connection, it may be that other emerging adults experience similar tensions while providing care for sick or dying parents.

Phase II- Qualitative Content Analysis

In order to address Research Questions 3 and 4, I examined the online posts of emerging adult caregivers using dialectical tensions as a sensitizing construct. My analysis revealed one primary dialectical tension emerging adults experience while serving as caregivers for their parents—*sacrifice-reward*—and two additional tensions that are related to this primary tension: *independence-dependence* and *presence-absence*. Although these tensions are discussed separately below, I attempt to illustrate how each tension implies, influences, and gives meaning to the other throughout the caregiving process.

The contradiction of sacrifice-reward. The dialectical tension of sacrifice-reward was the most common tension expressed by the emerging adult caregivers in this study. Although this tension describes the gains and losses associated with the caregiving experience, “sacrifice-reward” is used to describe this tension because it is more reflective of the specific language these caregivers used to express their experiences.

What is unique about the specific tension of sacrifice-reward is that it seems highly related to serving as a caregiver during emerging adulthood specifically. Although it is almost certain that caregivers of all ages feel as though they make sacrifices when caring for loved ones, the caregivers in this study seem to view caregiving as a sacrifice for one specific reason: one does not typically serve as a caregiver during emerging adulthood. Becoming a caregiver when one is not “supposed” to be one, when one should be free to pursue one’s own life, frames the caregiving experience as something challenging and requiring much sacrifice. One young woman put it this way:

While all caregiving has its commonalities, being a young caregiver definitely has its own unique challenges. Being thrust into a caregiver role at a younger age, when my mom at the age of 57 had a debilitating stroke, I was faced with all the “common” caregiver challenges but at a time in my life when it was completely unexpected, with absolutely no warning. ... Being a caregiver, especially at a young age, is a huge sacrifice. I don’t regret it, but sometimes I can’t help but feel that I am missing out on some of the best years of my life. ... I wonder—if and when—will I have the opportunity too fulfill my own hopes and dreams? As a young caregiver, this is my biggest challenge and fear. (5h)

Clearly, this daughter considers the experience of caregiving during emerging adulthood unique because it was “unexpected” and during “the best years of [her] life.” Although she mentions that she does not regret serving as her mother’s caregiver, she does feel that it is “a huge sacrifice,” particularly because her “own

hopes and dreams” have been put on hold. Another young woman, who chose to have her ill mother move into her home, echoed this sentiment when she stated: “[A]t a time when I was anticipating my wedding and starting married life and thinking about changing careers and going back to school, I was not really emotionally or physically prepared for the role of caregiving” (22a). This example and the one above are just two of the many posts from young caregivers suggesting that caring for a parent is inherently more challenging when it presents itself unexpectedly or “too early” in the life span.

Considering that emerging adulthood is a time when possibilities in love, work, and worldviews are explored (Arnett, 2000), it is not surprising that nearly all of the sacrifices that the emerging adult caregivers made reference to were related to these issues. For example, one emerging adult daughter felt that she had to sacrifice her career and love life while serving as a caregiver:

Some days like today seem impossible. I’m working hard at the career and it’s getting me nowhere, and I’ve just completely lost myself and any near future chance to meet Mr. Right. At 24 [caregiving] is not what life should be about, but it is. (26a)

Likewise, a young man mentioned struggling with a similar issue:

[N]o matter what grand illusions I manage to weave into the fabric of my perception, the fact remains I cannot have a normal life. I have been single for almost three years, and I feel it inside changing me into a bitter old man before I am even a quarter-century old. I can’t have a girl over in this situation. (27a)

These emerging adults suggest that caregiving is not part of a “normal life” and “not what life should be about.” Therefore, it seems that because caregiving during emerging adulthood is nonnormative, it violates these emerging adults’ expectations of what “should be” normal during this time—pursuing their careers or romantic relationships. As a result, these young caregivers may feel required to make sacrifices in these areas in order to provide care for their parents. As one 21-year-old daughter said, “I have done everything for my dad. I’ve given up my dreams, and opportunities, and now it feels like my youth” (23a).

It is important to note that although these emerging adults find it difficult to make sacrifices to provide care for an ill parent, they often *want* to make these sacrifices for their loved ones. When one makes a sacrifice, it often implies that he or she has given up something for the sake of something else of greater or more pressing concern. In other words, some emerging adults are willing to make personal sacrifices for the sake of what is best for their parent. One young woman offered this insight:

As caregivers, we often (if not always) put our loved ones first. ... It’s us, after all, that have made the sacrifice. We do it because we love them and because we (most likely) are the ones in our family that are loyal, caring, and want to do the “right thing.” (5c)

Similarly, another emerging adult daughter suggested that she was willing to make sacrifices because not doing so would only intensify an already difficult situation: “At this age especially, I feel so many conflicting things and am so

overwhelmed, but the only other alternative is a nursing home (two states away), and I am not willing to let that happen” (9d).

What is more, some emerging adult caregivers are not only simply willing to make sacrifices to care for their parents, but they also find the caregiving experience rewarding. Many of the online posts that refer to the sacrifices that are required to provide care also include a statement about the rewards that come with caregiving. In other words, the discourse surrounding the sacrifices required for caregiving is often accompanied by an opposing discourse of reward. For example, one caregiver commented,

I know for me caregiving has been the hardest experience of my life, but in many ways has taught me more than anything else—so in a way I feel almost a little fortunate for having had the experience (though it feels very strange to say that, and of course I wouldn’t ask for the situation again).

(38b)

Here, we see that although this young woman views caregiving as the “hardest experience” of her life and something that she would never want to experience again, she also feels that it has been rewarding, that it has “taught [her] more than anything else.” It seems as though this young caregiver sees the sacrifices she is making as ultimately valuable. Similarly, another emerging adult stated that although she was struggling to “keep her career afloat,” she “love[s] taking care of [her] mom” and finds it “super rewarding” (11b). And yet another young caregiver commented:

I see now the experiences that I missed out on because I wanted to be available to my mom. It was a choice on my part, though I couldn't have lived with myself otherwise, and it's a choice I'll never regret as I became closer to my mother through caregiving than ever before. (43a)

Similar to research that suggests caregiving can provide one with a sense of purpose, mastery, and increased emotional closeness with his or her ill family member (Donorfio & Sheehan, 2001), this emerging adult daughter has grown closer to her mother through caregiving. Therefore, she considers it a "choice [she]'ll never regret," despite the sacrifices she has made.

It is clear that these emerging adult caregivers describe their caregiving experiences as both significantly challenging (requiring much sacrifice) and incredibly rewarding. Although these two discourses seem to oppose one another, they actually work together to create greater meaning. Baxter and Braithwaite (2010) maintain that "meaning making is a process that emerges from the struggle of different, often opposing, discourses" (p. 50). Thus, the discourses surrounding caregiving as sacrifice and caregiving as reward interpenetrate to create dialectical unity and contribute to a larger meaning. That is, the sacrifices an emerging adult makes in order to care for an ill parent make the rewards of caregiving meaningful. For instance, if caregiving were easy or required little sacrifice, the rewards of caregiving would hardly seem significant. Likewise, the discourse surrounding the rewards of caregiving give meaning to one's sacrifices. Rather than viewing sacrifice as an inevitable and terrible reality of caregiving, reflecting on the rewards of caregiving allows one to view sacrifice as something

that can ultimately bring one “closer to her mother” or “teach” one more about oneself, as illustrated in the online posts above.

Although it is important to recognize how these two discourses create greater meaning within the parent-child relationship, one must not forget that these are dialectical *tensions* and that emerging adults struggle with these opposing forces. For example, a post from one emerging adult daughter seems to suggest that sacrifices can sometimes appear to outweigh the rewards. Reflecting on an essay about the death of a parent she recently read, she posted:

I do admire the writer’s honesty in saying that caregiving doesn’t always have the rewards that, in our most generous and hopeful moments, we might ascribe to it. It’s like, great! Not only do you have to do the work of caregiving, but you have to be effective, strong, and compassionate too? Can’t you just be, you know, human? Tired and cranky sometimes? Suffering from a little compassion fatigue? (17a)

This idea that caregiving is sometimes void of obvious reward resounded in the post of another young caregiver: “People are out there being caregivers, in a crazy world where we just love and love and sometimes get something back from our loved one, and sometimes just don’t” (28a). As one can see, it is not always the case that both poles of the sacrifice-reward tension are experienced in tandem; sometimes one discourse seems to overwhelm the other.

Because sacrifice-reward is a dialectical tension that creates contradictory emotions and responses within relationships, several of the online posts suggested that emerging adult caregivers work toward managing this tension in their

relationships with their parent. One way the emerging adult caregivers in this study seemed to manage this tension was through *recalibration*—temporarily reframing or recalibrating the tensions so that they do not seem oppositional (Baxter & Montgomery, 1996). Similar to the idea that the co-presence of each dialectical tension creates greater meaning, the caregivers noted that although the experience of caregiving can be both very rewarding and so challenging that the rewards are too difficult to see, the entire experience ultimately leads to something greater. For example, a young woman caring for her mother posted:

My time caring for my mother was the hardest thing I have ever done, but I would not take back one minute of it. I feel that her strength in addition to the opportunity to care for someone more than I care for myself has made me into the person I am today. I truly feel that I am a better, stronger person for the experiences I had with her and her condition. (9a)

One can see that this particular emerging adult reframed her experiences during caregiving—the good and the bad, the rewards and the sacrifices—as that which incited personal growth, making her a “better, stronger person.”

The dialectical tension of sacrifice-reward was the most frequent tension that emerged from the analysis of the online posts. This may be a result of the fact that emerging adulthood is marked by identity exploration and discovering new life directions; thus, emerging adults who find themselves serving as caregivers at this point in the life span may feel that doing so requires significant personal sacrifices. At the same time, many young caregivers find the caregiving experience very rewarding, and the interplay of the opposing discourses of

sacrifice and reward often creates greater meaning within the caregiving experience. Voicing the discourse of reward without acknowledging sacrifice reflects only a portion of the meaning that this dialectical tension creates within the caregiving relationship.

An emerging adult rarely expects to serve as a caregiver for a sick or dying parent so early in the life span. Consequently, he or she may feel that much is sacrificed in order to do so—careers, relationships, friendships, and ultimately one’s independence or freedom. Because emerging adult caregivers often feel that they must sacrifice their autonomy in order to care for a dependent parent, the specific sacrifice emerging adults in this study most often referred to was the sacrifice of one’s freedom or independence. Incidentally, an analysis of the online posts also revealed the dialectical tension of independence-dependence.

The contradiction of independence-dependence. The dialectical tension of independence-dependence is related to the broader primary tension of sacrifice-reward because the loss of independence is described as a particular sacrifice emerging adult caregivers must make. However, this tension is differentiated by the fact that the specific sacrifice of one’s autonomy is rarely accompanied by a sense of reward. The tension of independence-dependence, rather, refers to an emerging adult’s desire to maintain a sense of autonomy during caregiving, while simultaneously desiring to “be there” for a dependent parent. In other words, this tension is a result of a young caregiver’s need/desire for independence on the one hand and the parent’s dependence on the child for care on the other.

Emerging adult caregivers in this study often mentioned that they struggled to maintain their independence in the face of caring for a parent who became dependent on them for care after a diagnosis. For example, one young woman noted, “The luxury of having freedom and a ‘me-centric’ lifestyle are long gone” (5b). In a later post this same caregiver says,

There are many challenges unique to young caregivers out there, [such as] freedom and time. Time to do what a young person should be doing: having fun, building their career and family, traveling, finding love, going out with friends, etc. (5i)

As mentioned above, losing one’s freedom or independence, though likely experienced by caregivers of all ages, seems particularly salient for emerging adult caregivers, as they tend to expect freedom and believe “having fun, building their career and family, traveling, finding love, going out with friends” are things they “should be doing.” This notion is reflected in an emerging adult’s response to other caregivers’ posts:

I absolutely applaud all of you for the caregiving you are doing at such a young age. You live it everyday and give up so much, most of all your freedom and innocence, which every young person should have, but it is quickly taken away the moment your loved one becomes ill or disabled. (31a)

It is quite evident that young adults experience a sense of lost autonomy, which is often expected during caregiving. However, the result of such a “quick” and extreme loss of autonomy during emerging adulthood is that young caregivers

often feel misunderstood by their friends and peers. A 25-year-old daughter caring for her quadriplegic mother wrote, “I see so many of my friends just hanging out, concentrating on their own lives and being carefree. They have no clue!” (9c). Similarly, another emerging adult daughter posted: “Like many of you have said, my friends are encouraging but don’t really understand what it is like. I find myself being extremely jealous of them and their ‘carefree’ lives” (7a). It appears that an emerging adult caregiver’s sense of lost autonomy is intensified when their experiences are juxtaposed with that of emerging adults who are non-caregivers. Caregiving during emerging adulthood is nonnormative; thus, it may be difficult for other emerging adults (particularly friends of caregivers) to understand the loss of independence that comes with caregiving. Many emerging adults feel that unless one has been a caregiver, he or she will never “really” understand them. As one young woman said, “While most of my friends have been supportive, they have never been caregivers. Their intentions are good, but at the end of the day, they can’t relate” (5i). Because emerging adult caregivers often feel misunderstood by their peer group, they may experience a sense of loneliness and isolation. As one 21-year-old caring for her father said, “It does feel lonely because none of my friends are going through anything like this” (8a).

Many of the caregivers in this study suggested that the most difficult aspect of caregiving was experiencing a loss of independence and freedom, and this loss has significant consequences for emerging adults in particular. However, it is important to remember that one’s sense of lost autonomy does not occur in

isolation; as Bakhtin reminds us, “The most important acts constituting self-consciousness are determined by a relationship toward another consciousness” (Baxter, 2007, p.253). Said otherwise, one’s sense of lost autonomy is a product of his or her (communicative) relationship with another. For these emerging adults in particular, their loss of independence was directly related to their sick parent’s new dependence on the emerging adult child. This is evident in a statement made by one young caregiver: “Now more than one year later, with the dust settled, she is gaining independence, and I am gaining some of my life back” (5j). Most of the online posts, however, did not express caregivers regaining their life (sense of autonomy), but rather expressed the difficulties of having a parent depend on them. One young woman, describing her experience of having her mother depend on her, noted:

[My mother] also told me that she’s so glad she has me, that I’m the only one she can count on and the only one that does things right. That second part may not be a blessing, as it makes it hard to have any help. (11b)

Sometimes emerging adult caregivers expressed their willingness to give up personal autonomy, despite the fact that it was challenging. One daughter explained how her first priority was to care for her mom, despite the fact that her mother’s dependence resulted in a loss of her personal independence: “Sometimes I get frustrated because I can’t do the things that other people my age can do, but when it comes down to keeping my mom at home and happy, it’s really my top priority” (9c). Another young caregiver noted something similar—“Taking care of [my mom] is my first priority over my own needs” (11a). Although the young

caregivers in this study often expressed that losing some of their independence is difficult, these examples illustrate how some caregivers are willing to do so for the sake of their parent.

It is not enough to say that the dialectical tension of independence-dependence merely exists within the caregiving experience, as this tension ultimately creates meaning within the parent-child relationship. For instance, several online posts indicated that the dialectical tension of independence-dependence resulted in “role reversal” or a significant change in the traditional conception of the parent-child relationship:

One challenge is the loss of a relationship as you knew it. Role reversal. While I watch my friends mom’s support their daughters and enjoy their grandchildren; walking down aisle at weddings, babysitting, etc. Even the typical annoying things—mothers getting overly involved, preaching on how to raise their grandchildren. I will not have that. The nature of my relationship with my mom has changed. I am thankful for our relationship now; but it has been redefined and my mom can no longer be “a mom” to me. (5i).

This same emerging adult daughter later recounted her experience Christmas shopping with her mother after her mother’s stroke:

My mom had always been amazing at picking out gifts before the stroke. She couldn’t do it. I had a meltdown. And she cried. We had worked hard for over a year for her recovery. And she wanted to be the mother that I needed her to be. She simply couldn’t. (5j)

It appears that when an ill parent becomes dependent on an emerging adult child, the relationship is considerably, and sometimes permanently, altered. Although a reversal in the parent-child roles may be experienced by older adults caring for elderly parent as well, it seems that emerging adults may have a more difficult time adjusting to these changes, as they often do not see themselves as adults. Becoming a “parent” during a time when one still needs his or her parent (e.g., “the mother that I needed her to be”) or still feels dependent on a parent for emotional or financial support, may make it exceedingly difficult for emerging adults to cope with the role reversal that often accompanies caregiving.

Because the reality of parent-child role reversal can be hard for young caregivers to contend with, emerging adult caregivers and their parents may find themselves attempting to manage the dialectical tension of independence-dependence. The online posts from emerging adult caregivers suggest that they attempt to communicatively manage this tension in several ways. One approach, similar to the technique of managing the sacrifice-reward tension, seemed to be *recalibrating* or reframing the tension in order to transcend the opposing poles without denying or altering their presence. The reframing of this tension between independence and dependence was achieved by altering one’s expectations of his or her parent:

I will always want my mom back; that is a feeling that will never change.

But I need to accept that she can’t be exactly what I want her to be.

Perhaps in letting some of my expectations of her go, we will both be more relaxed and just be able to enjoy each other’s company for what it is.

It may not be how it was before the illness struck, as a defined mother and daughter relationship, but now just as two people who love each other. (5j)

This quote beautifully illustrates how this tension has been recalibrated and transcended within the parent-child relationship. The daughter does not deny that this tension exists, and she acknowledges that she “will always want [her] mother back.” Instead, she embraces the fact that the parent-child relationship has been forever altered by the change in her autonomy and the change in her mother’s dependence, and she has, therefore, adjusted her “expectations” of her mother. It is no longer necessary for them to define who is “mother” and who is “child” because they have allowed their love for one another to ultimately define their relationship.

In addition to recalibrating the independence-dependence tension, it appears that the emerging adult caregivers in this study attempt to manage this tension through *segmentation*. Thus, a young caregiver may attempt to maintain or “get back” some of their autonomy by removing oneself from the caregiving situation for some time and pursue his or her own interests. One caregiver expressed:

Here [is something] I’ve done to make me feel like a person again: Try something new that you have always wanted to do. This will give you a sense of accomplishment for your own goals. ... As caregivers, we put a lot of our normal lives on hold, so it feels great when you do something that otherwise you never made time for. (31b)

For many young caregivers, maintaining a sense of independence, attempting to feel “like a person again,” or pursuing their “normal lives” required taking “breaks” from caregiving. For example, one young woman advised another caregiver:

You need to give yourself some “me time” as hard as it may seem. Even taking a walk in a park and sitting on a bench for half an hour. Twenty-five is still young to have so much resting on your shoulders. (14a)

Interestingly, despite the fact that many of the emerging adult caregivers suggested that they took breaks or “made some ‘me-time’” and advised others to do the same, many of the posts that espoused the importance of removing oneself from the caregiving situation in order to regain a sense of autonomy also expressed the dialectical tension of presence-absence. In other words, managing the tension of independence-dependence through segmentation (choosing to be independent in certain areas of life outside of caregiving) resulted in yet another tension for caregivers: feeling torn by their desire to be present—to “be there” for their parent—and by their recognition that taking breaks from caregiving may be necessary and healthy.

The contradiction of presence-absence. While the dialectical tension of independence-dependence refers to the loss of freedom and autonomy that often accompanies caregiving, the presence-absence tension is related to independence-dependence but is nuanced by a specific loss that comes with the loss of independence: personal time and space for oneself. Young caregivers often feel torn between their desire to be near or physically present with their ill parent and

their desire for time apart from their parent. More specifically, they desire to be—or feel that they ought to be—physically present with their ill parent as much as possible and, thus, feel guilty when they are apart from them or are “absent.” Interestingly, this dialectical tension seems to manifest itself in two distinct ways, depending on the caregiving context. In other words, caregivers who feel strongly inclined to be physically present with their parent experience the presence-absence contradiction differently than do those who lean more toward absence.

For emerging adult caregivers who experience a strong desire to be physically present with their parent, it is often the case that they find it difficult to “take breaks” from caregiving and usually feel guilty when they do. These caregivers’ posts often include “reminders” to themselves and to others that time away from their parent is normal and healthy. One emerging adult daughter said,

[T]he truth is, as much as I don’t like to hear it, it is important—no, it is a necessity—to make time for yourself if you want to avoid total burnout. I have to admit, I am not an expert at doing this myself. Sometimes I have to literally force myself to ignore all the things that need to be done and concentrate on doing something nice for myself. ... I shouldn’t feel guilty for having as much of my own life as I can get. (5b)

This caregiver seems to recognize that it is “a necessity” to make time for oneself so as to remain healthy or “avoid burnout,” but we can see the tension here as she says she must “force” herself to do so. Although she clearly states that she “shouldn’t feel guilty” for being absent, the fact that she reminds herself of this may be an indication that she has, in fact, felt guilty in the past for being away

from her mother. It is important to take note of this, as many posts reflecting the presence-absence tension also mentioned the idea that both parent and child may experience feelings of guilt. For example, one emerging adult daughter stated, “[My mom] of course feels guilty every time I miss work and insists I go sometimes even when it’s not a good idea” (11a). The daughter’s insistence to be present (perhaps motivated by guilt, though this was not made explicit in the post) results in the mother feeling guilty as well, which is reminiscent of Burles’ (2006) findings that mothers with breast cancer can have difficulty accepting care from family members because they do not want to “burden” them with extra work and stress. Thus, the dialectical tension of presence-absence may lead to feelings of guilt for both the parent and child, as the parent may feel guilty for “burdening” the child who is always present and advise the child to take time for oneself, while the child may feel guilty for doing so.

For these young caregivers who felt inclined to be frequently present (i.e., desired to spend the majority of their time with their parent) and felt guilty whenever they were absent, fellow caregivers offered this advice: “Do not allow guilt to run the situation. It is the wrong emotion to drive it, and it translates to resentment, which ultimately backfires on the whole thing” (2a). Or: “You need breaks built in, and not just for an hour or two. ... Don’t feel guilty asking for any of this, because no human could keep going the way you are” (45a). The advice here seems to not only suggest that caregivers should not feel guilty, as time for oneself is absolutely necessary, but this advice also indicates that one way emerging adult caregivers manage the tension between presence and absence is

through *segmentation*—that is, choosing when to be present with the parent and when to set aside other times (albeit more infrequent) to be absent.

Unlike the caregivers above who erred on the side of being “too present” and were advised to take “more time for themselves,” the caregivers who felt strongly inclined to remain absent, felt that they ought to spend “more time with their parent.” As one young woman, in her blog titled “Guilt,” stated,

Sometimes when I leave the nursing home, even though I don't even go that often, I'm just so relieved to be out of there and in the fresh air heading back to my own life. But then I feel bad about that because I know the person I have just been caring for can't leave—that *is* his life. And I think I should, I don't know, be more present? Enjoy spending time with him more? Be less eager to leave? And I think I should go more often, to give his other caregivers more of a break. And so there's a lot of guilt. (38a)

In this instance, the daughter is left with guilty feelings because she believes that she *should* “be more present” and “enjoy spending time” with her father, rather than feeling “relieved” when she leaves the nursing home. This caregiver's tension between her eagerness to leave and her sense that she “ought” to be more present is distinctly different from that of the young caregivers who were more inclined to be present even when they recognized that they “ought” to make time for themselves.

Interestingly, the advice offered to young caregivers who felt guilty about their preference for absence and their eagerness to leave was distinctly different as well. In response to the blog post “Guilt,” a young caregiver wrote:

I know exactly what you’re talking about. ...From my perspective, presence can be complete and total in one moment. So even if you're not there X amount of days or whatever, if you can be totally present in the moment while you are there, then you are being absolutely supportive.

(46a)

Here, the fellow caregiver does not suggest segmentation as a way to manage the presence-absence tension. Instead, she seems to reframe or *recalibrate* what it means for one to “be present,” suggesting that in order to be present, one does not have to spend the majority of his or her time in the physical presence of the parent, but rather has to remain open and attuned to the parent in the moment. In a similar vein, the advice offered to the caregiver about managing guilt also greatly differed from the advice given to caregivers who preferred being physically present with their parents:

I think it's totally natural to feel a sense of guilt because really, if you didn't, you wouldn't be completely human. [Guilt] will probably always be present, but that really just means you're thoughtful and empathetic—good qualities to have overall, but unfortunately probably result in some guilt along the way. (46b)

Unlike the emerging adult caregivers who were advised to *not* feel guilty because being absent was healthy and necessary, this caregiver is told that guilt is “totally

natural.” What is more, guilt is reframed as not only natural but as something positive, as it suggests one is “thoughtful and empathetic.” The writer also indicates in her last sentence that perhaps one’s guilt is *not* a result of being absent too often, but rather it is a result of her thoughtfulness and empathy.

Taken together, the posts above illustrate that emerging adult caregivers often struggle to negotiate when and how to “be there” for their ill parent. It may be the case that emerging adults’ decisions to be absent is based on their sense of autonomy loss; therefore, they choose to be absent to “get back” or maintain some sense of independence. On the other hand, for those who find it difficult to leave their parents, it may be that they have sacrificed so much of their autonomy—their identity, really—that it seems nearly impossible to remove themselves from the caregiving situation, as they have lost sight of who they are outside their role as caregiver. As one young woman mused:

I wonder how it feels when you’ve been a young caregiver, but then you are no longer in that position. It must be very confusing and difficult, in a way, to not only lose your family member but also, to certain extent, a part of your identity at the same time. (38b)

Summary. The dialectical tensions discussed above are highly interrelated and their interplay may significantly impact the emerging adult caregiving experience. An emerging adult may find it incredibly challenging to serve as a caregiver during a point in the life span when it is unexpected, as it requires much sacrifice and can limit one’s sense of autonomy. As a result, one may find oneself pulling away from his or her parent as a way to maintain

independence. Or, conversely, an emerging adult caregiver may find it difficult to separate oneself from the caregiving role, which can result in patterns of codependence and loss of individual identity—ultimately impacting the well-being of both parent and child.

The findings of this qualitative content analysis are significant because they provide insight into how caregivers manage dialectical tensions not only with their ill parent but also with fellow caregivers. The advice offered to one another via online support groups (e.g., to take breaks from caregiving to maintain autonomy, to reframe feelings of guilt, etc.) indicates that communicatively managing the dialectical tensions inherent to the caregiving experience can, in fact, occur outside of the parent-child relationship. These online support groups appear to be a way for young caregivers to actively combine resources and problem solve collectively as a group. The fact that the emerging adults in this study jointly managed (or attempted to manage) some of the dialectical tensions of the caregiving experience points to the value of, and need for, caregiving support communities created for young caregivers specifically.

The Many Facets of the Crystal: A Comparison of Findings

Ellingson (2009) reminds us that “juxtaposing different ways of knowing through crystallization reveals subtleties in data that remain masked when researchers only use one genre to report findings” (p. 11). Making use of both autoethnography and qualitative content analysis, and comparing the findings from each, affords us a richer understanding of the emerging adult caregiver experience. The qualitative content analysis (Phase II) offers valuable insight into

the experience of caregiving for emerging adults, highlights the most common dialectical tensions they encounter in their communication with their ill parent, and suggests that these tensions are managed both within the parent-child relationship and communally with other caregivers. The autoethnography phase, on the other hand, offers a detailed description of the lived experience of mother and daughter and points to the subtle nuances that are often overlooked when utilizing methods with a broader scope, such as content analysis.

When comparing the findings from each phase of this study, we can see some significant similarities between my personal experience and that of other emerging adult caregivers. Both point to the sudden and often radical loss of autonomy that comes with caring for a parent during emerging adulthood. Although I describe my tension as separation-connection while the tension of the other young caregivers is best described as independence-dependence, both imply the obvious and ongoing negotiation of autonomy within the context of caregiving. Emerging adulthood is a time already marked by a desire for autonomy and a quest for new personal directions. As such, serving as a caregiver during this time—and experiencing a reversal in the parent-child relationship—appears to be a difficult transition for emerging adult caregivers, just as it was for me. It seems, then, that the struggle to maintain independence while caring for a parent who has become increasingly more dependent is a salient issue that many emerging adult caregivers share.

In my description of the separation-connection dialectic, I explain that there were times I felt almost incapable of leaving my mother's side, which is

reminiscent of the presence-absence tension discussed in Phase II. Like me, other emerging adult caregivers described how difficult it is to be away from their parent and how they often feel guilty when they are not physically present with them. However, it seems important to point out that although the separation-connection and presence-absence tensions are similar, there are some notable distinctions. My tendency for staying both physically and emotionally connected to my mother was often a result of a sense of impending loss. Although I often found it difficult to “take breaks” and allow others to assist with caregiving, it was significantly more difficult to do so when I desired closeness and connection with my mother because I felt I was losing her. Although this may have certainly been the case for other emerging adult caregivers, it was not reflected in their online posts. The presence-absence tension seemed to be more distinctly marked by a sense of spatiality and temporality—that is, a literal need for “some space” or “me-time”—rather than a need for *emotional* closeness to (or separation from) a parent. Nonetheless, both findings point to the fact that maintaining healthy boundaries within the parent-child relationship may be a significant struggle for emerging adult caregivers.

Interestingly, a comparison of the findings from both phases also reveals some considerable differences. For example, the most common tension for the emerging adults in the Phase II was that of sacrifice-reward. Although I would certainly attest to the fact that caregiving for a parent during emerging adulthood requires incredible sacrifice, my narrative does not seem to reflect feelings of gratitude for my experience. Is it true that I have grown as a person from my

experience? Yes. But would I ever frame the experience of watching my mother in pain and losing her to cancer as ultimately rewarding? No. One reason for this difference in perspective may be that my mother's diagnosis was terminal, while other emerging adults may be caring for parents with long-term/chronic, nonlife-threatening illnesses or with conditions that are progressively improving.

Because their experience is not marked by impending loss, unstoppable change, and disease progression, it may be easier to frame caregiving as a rewarding experience. As Baxter et al. (2002) remind us, one tenant of relational dialectic theory is situatedness, or the notion that contradictions are often indigenous to specific situations and are contingent upon context. As such, the very existence of a tension and how that tension is manifested and managed in communication can depend on factors such as the relationship type, the quality of the relationship before and during caregiving, the specific disease diagnosis, and whether or not the diagnosis is terminal (to name a few). The situatedness of dialectical tensions became quite clear to me during a discussion I had with my aunt (my mother's sister) several months ago. I was telling her about the work I was doing with my autoethnography and my experience as a caregiver during emerging adulthood. When I told her how my mom and I had become very closed toward the topic of death, she looked very surprised and explained that she and my mother had discussed the fact that she was dying on several occasions leading up to the day my mother died. I was stunned when she told me this, as I had believed my mother never accepted she was dying and was completely closed to any end-of-life conversations. However, hearing this helped me to see that our closedness

toward death was a unique, communicative element inherent to our specific mother-daughter, caregiving relationship. It was not as if my mother and I were psychologically closed toward the reality of death—as we were able to discuss death with other people—rather, our preference for closedness about end of life with one another was created and maintained within our interpersonal communication.

During the analysis of the online posts, I was surprised to find so few posts that indicated this dialectical tension of openness-closedness toward discussing death. It may be the case that these caregivers did not experience this tension at all in the parent-child relationship, particularly if their parents were not terminally ill. Or, it could be that they did experience this tension but were so closed toward conversations about death, they were hesitant to even express the notion of losing their parent in the online setting. Or, perhaps many of these caregivers experienced this tension, but their online posts (which, of course, are not actual parent-child dialogue) did not indicate such a distinctively communicative phenomenon. If this is the case, without the autoethnography phase of this study, this specific tension may have been left uncovered. One benefit, then, of adopting crystallization as a framework is its capacity to access both the general and specific expressions of dialectical tensions within relationships.

Chapter 4: Discussion

Collectively, the findings presented herein extend scholarship in family communication and caregiving in a manner that both furthers the discipline and

can translate into healthcare practice. The theoretically grounded findings broaden our understanding of the complexity of the parent-child caregiving experience during a developmental period that is largely understudied. This life-span perspective of communication, health, and family advances knowledge about emerging adult caregivers' unique communicative needs and challenges.

Additionally, using relational dialectics theory as a framework enriches our understanding of critical caregiving issues, such as the communication impasse about death and dying and the adaptive and maladaptive functioning of family communication when coping with illness. Finally, the methodological design of this crystallized text demonstrates an innovative approach scholars can utilize to capture the many facets of family communication in the context of health, illness, and death. The implications these findings have for family and health communication, as well as their meaningful utility for healthcare practice are further outlined below.

Scientific and Theoretical Contributions to Family and Health

Communication

Caregiving during emerging adulthood is a nonnormative life event, and the findings of this study suggest that emerging caregivers perceive it as such. It violates one's expectations of what he or she "should" be doing during this time—pursuing possibilities in "love, work, and worldviews" (Arnett, 2000, p. 469). As a result, emerging adult caregivers must negotiate a new sense of independence when faced with caring for an ill parent. However, because emerging adults often feel that they are too young to face losing a parent, they

may feel torn by their desire for independence, absence, or separation on the one hand and their desire for connection and presence on the other. Considering that some emerging adults may use dysfunctional strategies to manage these tensions when faced with impending loss (e.g., being “too present” or closing themselves off to conversations about death), healthcare workers should be aware that emerging adults may resort to maladaptive coping strategies when caring for a terminally-ill parent.

Relational dialectics theory proved to be a very fruitful and productive framework for examining the experiences of caregiving and loss during emerging adulthood. Not only did the findings indicate which tensions are dominant during these experiences, how they are managed, and the meaning they create within the parent-child relationship, but the findings also suggest that the ways in which the parent and child manage the dialectical tensions that permeate the caregiving experience often serve as coping mechanisms. For example, the findings of the study’s first phase illustrate that a mother and daughter may cope with inevitable loss by denying the existence of one pole (openness toward conversations of death) and privileging closedness. This supports research suggesting that family communication can become restricted and less verbally explicit as members attempt to protect one another from impending death (Beach, 1995; Pecchioni et al., 2006). However, the findings of this study are distinctive because they suggest that family members’ closedness toward death (i.e., an end-of-life communication impasse) can transfer over into the healthcare setting. As mentioned in the autoethnography, one way I attempted to “protect” my mother

from death was by attending all of her doctors' appointments. Because closedness toward death was a communicative component of our mother-daughter relationship, neither of us would inquire about her prognosis in the presence of the other. As a result, the doctors were never prompted to engage in any end-of-life discussions. Although the physicians may have interpreted our silence to mean that we already understood that my mother was dying, my mother and I took their silence to mean that we could continue to pretend as if things were "normal." This is significant because end-of-life communication impasses are typically conceptualized as either a health communication phenomenon (Lannamann, Harris, Bakos, & Baker, 2008) *or* a family communication phenomenon. The findings of this study, however, suggest that the impasse may actually result from an interplay of these two communicative contexts.

Additionally, using dialectical theory to examine the caregiving experience gives us new insight into the prominent theme of "control" and the cancer experience, which has been examined in various disciplines of scholarship. One's ability to exert control over cancer is typically conceived as a psychological or cognitive strategy (Osowiecki & Compas, 1998). However, this study suggests that cancer patients and their family members may attempt to control the disease communicatively through managing tensions. For example, they may privilege predictability and become highly resistant to change, or they may privilege closedness and deny openness toward discussions of death as a way to maintain a sense of normality and, thus, "control" the disease. However, attempting to control the disease by privileging predictability and not adapting to inevitable

change can be an unhealthy coping strategy. In fact, previous research has shown that both inflexibility/rigidity (e.g., privileging predictability) and denial/avoidance (e.g., privileging closedness toward end of life conversations) function maladaptively in individuals' ability to cope with stress. For example, Carver, Scheier and Weintraub (1989) suggest that using the coping strategy of denial—an emotion-focused coping strategy that attempts to manage one's stress level rather than the stressor itself—may cause the stressor to become more serious and more difficult to cope with in the future. Likewise, research has shown that inflexibility in the face of stress and change can compromise a family's ability to cope in ways that enhance well-being. For example, the Circumplex Model of Marital and Family Systems (Olson, Russell, & Sprenkle, 1980, 1983), which is comprised of two curvilinear dimensions—family cohesion and family adaptability—suggests that optimal family functioning is typified by a balance on both cohesion and adaptability. According to the model, families that are highly enmeshed and rigidly inflexible are considered “extreme” families. They tend to resist change, which can be maladaptive in their ability to cope with stress and function as a family. Considering this, it is necessary that healthcare professionals be aware of communicative patterns of denial/avoidance and inflexibility/rigidity, particularly in the parent-emerging adult child caregiver relationship, so that they may help the patient and caregiver communicatively cope with cancer in more productive, healthy ways.

This study also provides keen insight into the mother-emerging adult daughter caregiving experience. The often dysfunctional ways in which my

mother and I attempted to manage the dialectical tensions within our relationship led to maladaptive coping strategies, such as denial and closedness toward end-of-life discussions. Because the mother-daughter relationship can be the most significant relationship in a woman's life (Fischer, 1986), it may be the case that one would do anything to preserve this relationship in the face of impending loss. And this may be especially true for an emerging adult daughter who feels that she is too young to lose her mother. As a result, emerging adult daughters and their ill mothers may resort to dysfunctional strategies to manage dialectical tensions and close themselves off to important end-of-life discussions—despite the fact that doing so can ultimately lead to confusion and regret when one is forced to let go of her mother. In fact, Fisher's (2010a) study of how communication between mothers and daughters can serve to both adaptively and maladaptively affect women's adjustment to breast cancer indicates that avoidant behavior is more evident in young-adult daughters with diagnosed mothers. Moreover, mothers felt the behavior functioned maladaptively within the relationship. Interestingly, young-adult daughters were the only daughters in the study who recalled withdrawing from their mothers, which suggests that this communicative behavior may be particular to the emerging/young-adult age group. However, despite the unhealthy coping strategies that a mother and daughter may resort to during the caregiving experience, it is important to note that caregiving can create an intense bond between mother and daughter—a bond they may never again share with anyone else. A nonnormative life event like caring for a parent with a terminal illness so early in the life-span can create an unparalleled sense of emotional

closeness between mother and daughter that is certainly rare during emerging adulthood.

Finally, the findings of this study reflect the value of adopting crystallization as a methodological framework. Not only did the blending of paradigms and methods serve to validate my findings—as both the autoethnography and content analysis highlight similar experiences among emerging adult caregivers—but it also illustrates how two partial accounts can work in concert to create a richer whole. While Phase II “let show” the experiences of a broader population of emerging adult caregivers, this method captured more of the in-the-moment dilemmas during caregiving (which is the function of online support groups). The autoethnography, on the other hand, offered a more comprehensive and longitudinal account of the *process* of caregiving and the transition into death/dying and loss. Although both phases of this study could exist as autonomous studies, presenting them together allows for a deeper, more profound understanding of the caregiving experience during emerging adulthood.

Practical Implications

This study has numerous practical implications for healthcare providers and professionals working with patients and caregivers. In particular, this study illuminates tensions that are often never voiced but need to be talked about among patients, caregivers, and practitioners. For instance, the findings of the first phase of this study indicate that an emerging adult may have difficulty letting go of one’s parent. As a result, he or she may develop communication patterns that

inhibit the initiation of end-of-life conversations. In my experience, for example, I did everything I could to avoid these conversations and was distressed and angry when the palliative care physician initiated this discussion. I now see, however, that protecting my mother from this conversation was actually delaying the relief and contentment she experienced once she finally openly accepted her inevitable death. Most patients believe that it is their physicians' responsibility to initiate end-of-life discussions (Lannamann et al., 2004). Still, these conversations often do not occur soon enough in the disease process, if they happen at all. It is absolutely essential that healthcare professionals are aware that some family dynamics, such as the codependence and protectiveness that occurred in my relationship with my dying mother, can limit opportunities for end-of-life-conversations, and avoiding these conversations can negatively affect both the dying person's and his or her family members' ability to cope with loss (Pecchioni et al., 2006).

Physicians may need to speak with patients and their caregivers separately in order to encourage them to ask the questions they may be afraid to pose when the other is present. Ultimately, physicians must become more proactive about initiating end-of-life discussions, despite the difficulty and pain that inevitably accompanies these conversations, as it may significantly affect the well-being of both terminally-ill patients and their emerging adult caregivers as they face inevitable loss.

My hope is that the personal narrative included in the first phase of this study will bring awareness to healthcare professionals of the need to actively

initiate these discussions, especially if emerging adult children are serving as primary caregivers for their patients. Perhaps this illness story has practical value for narrative medicine (see Charon, 2006) and the medical humanities (see Aull, 2010), as it provides insight into the authentic, lived experience of caregiving and oncology care.

The findings of the second phase of this study illustrate that emerging adult caregivers often struggle to maintain a sense of autonomy while providing care for a parent who is highly dependent on them. It is often the case that these caregivers want to provide the best care possible for their parents and, as such, find it difficult to prioritize their own needs or take time for themselves. Moreover, they may never voice this dilemma to practitioners or loved ones for various reasons, including the sense that they are alone in the caregiving role. For example, many of the young caregivers in this study mentioned that they felt most overwhelmed when they sensed a lack of support from friends or other family members. As one emerging adult daughter said, “[Caregiving] is a life changing experience, and being left alone while doing it is so scary” (9b). Another young caregiver commented, “There is no help from any corner. To be a caregiver is to be alone” (20a). Some of the participants said that they believe friends and family are less inclined to offer help because they see the caregiver as young and able-bodied, possibly needing less assistance than would a much older adult taking care of an elderly spouse, for example.

We are already aware of the fact that emerging adult caregivers are understudied and underserved, and if it is the case that these young people also

sense little support from family members or healthcare professionals, it is imperative that more support and resources be made available to them during the caregiving experience. Caregiving requires time, energy, physical demands, and financial cost, which can lead to relational strain and emotional exhaustion for any caregiver (Pecchioni et al., 2006). Considering emerging adults are at such a vulnerable point in the life span, healthcare professionals should make it a point to connect these caregivers with the necessary resources (e.g., support groups, counselors, home health agencies, etc.) to prevent them from becoming overwhelmed.

Limitations

This study may be limited by the fact that the first phase consists of an examination of one single experience. Similarly, the fact that the experience is one of a Caucasian, middle-class, female emerging adult may make the findings difficult to “generalize.” However, Ellis and Bochner (2001) propose that an autoethnography is meaningful for the reader in the sense that “our lives are particular, but they also are typical and generalizable since we all participate in a limited number of cultures and institutions ... likewise [autoethnography] can tell [readers] about unfamiliar people or lives” (p. 751).

While comparing data from multiple methods is a validating tool to enhance the credibility of findings, the method choice is worth discussion. For the second phase of this study, I would have liked to have observed actual communication exchanges between parent and child or traditional face-to-face support groups for young caregivers. However, emerging adult caregivers are a

difficult population to access and caregiving is a sensitive and private human experience. Moreover, the Internet seemed most conducive for this particular study, given the absence of any support groups for emerging adult caregivers in the city in which the study was conducted. One benefit of using online methods is it allowed for an examination of posts from caregivers residing all across the U.S. One limitation, on the other hand, is not all emerging adult caregivers have access to the Internet. According to the U.S. Department of Commerce (2010) persons in rural areas are less likely to use the Internet, and minorities in these areas exhibit a lesser propensity to use broadband than their counterparts in urban areas. Consequently, the findings of this study may not be representative of the entire emerging adult caregiver population. Further research should be conducted via the aforementioned alternative methods when possible.

Areas for Future Research

Considering that much of the caregiving literature is centered on the “average” caregiver (usually middle-aged women), more research is needed that focuses on emerging adults specifically, as they are a large caregiving population and their experience is not widely understood. The current literature would benefit from studies that examine whether caregiving, loss, and grief are experienced differently by emerging adult sons as compared to daughters or by children who care for fathers as compared to mothers. Also, it is important to address how the emerging adult caregiver experience varies when one takes into account the quality of the parent-child relationship before and during caregiving, the parent’s specific diagnosis, and whether or not the diagnosis is terminal.

Although the emerging adult caregiver population is a difficult one to access, efforts should be made to conduct more studies that adopt varying methodologies and include a larger, more diverse group of participants. Moreover, this study suggests that emerging adult daughters caring for their mothers may communicatively manage tensions during caregiving in a very distinct (and sometimes unhealthy) manner. Therefore, studies that incorporate qualitative interviews with mothers and daughters would provide great insight in this area.

The findings presented here indicate that adopting crystallization as a methodological framework can grant one access to both general experiences and the detailed, subtle nuances that can be overlooked in studies that utilize one method of investigation. Therefore, research concerning lived experiences like caregiving, oncology care, family communication, health communication, death, and grief would be greatly served by researchers who are open to producing crystallized texts.

Finally, very little of the extant research concerning grief focuses on emerging adults. Many children still depend on their parents for support and comfort during emerging adulthood, and they rarely expect to lose a parent at such a young age. Consequently, grieving the death of a parent may be an incredibly complicated and confusing experience for an emerging adult. In light of this, I have chosen to end this study with an epilogue that may provide insight into this unique process and, at the same time, provide direction for future research in this area.

Epilogue

Now, with the one year anniversary of my mother's death come and gone, I find myself bringing my research to a close. As I look back on my journey, I realize my research has not only been shaped by my personal experience but that I have been shaped by my research. Going into this project, I fully expected that writing a narrative would be a painful but necessary step in making sense of my experience and drawing meaning from it (which it was), but I did not expect that I would be so personally impacted by my ethnographic explorations. Coffey (1999) suggests that a researcher must reflect on how fieldwork can influence the researcher's construction of the self. While reading and re-reading (and re-reading) the online discussion posts, I found myself reliving much of my own experience. Because I am still grieving the death of my mother, the sorrow that others' stories stirred within me forced me at times to confront my own emotions and reflect on the grieving process. Doing so has helped me to see that much of my grieving centers on the dialectical tensions that I experienced before my mother's death.

As I grieve I am still overcome with an enormous sense of guilt for the independence that I desired as an adolescent and for not having pursued a closer relationship with my mother sooner. As an emerging adult, I was just entering a time in my life when I was ready to establish a more mature, interdependent relationship with my mother. However, she was diagnosed with cancer before our new relationship was able to fully develop, which causes me to question my initial desire to be close to her. Did I want to be close to her again because my

adolescent quest for independence was coming to an end, or was it because I was afraid I was going to lose her? Did it really take a terminal diagnosis for me to abandon my selfish desires and spend quality time with the woman who had sacrificed so much for me?

This same guilt is what motivated me to tell my mom just hours before she died that I hoped I had loved her well enough before she was sick. Although her response should reassure me, I cannot help but wonder if I would have been “the best daughter anyone could ever ask for” if my mother had not been dying of cancer. As I grieve, I am struggling most with the fact that I had desired a separation from my mother at all. In spite of all the research that suggests that the desire for independence during adolescence is normal and necessary (e.g., Burles, 2006; Laursen & Collins, 2004), I am unable to emotionally accept my behavior as normal.

It has been an interesting experience living with this guilt while simultaneously doing research for this study. After writing about the guilt I feel for having desired independence from my mother before her death, I came across Rando’s 1984 book, *Grief, Dying, and Death: Clinical Interventions for Caregivers*. In it, she states, “Because human relationships always contain some measure of ambivalence, a mixture of negative and positive feelings, and because our relationships, as ourselves, are not perfect, guilt will be a natural concomitant to the loss of another” (p. 31). Rando’s insightful commentary speaks to me both as a researcher and as one who is mourning a loss. As one who is mourning, I am comforted to learn the guilt I am living with is a normal part of the grieving

process, and I am relieved to hear it is common for the bereaved to recall and even exaggerate the negative experiences of their relationship with the lost loved one, while simultaneously “failing to remember” the positive (p. 31). And I cannot help but feel validated and relieved when Rando (seeming as though she is addressing me personally) says things like, “[T]he daughter who feels she should never be upset with her mother may suffer from guilt after the mother’s death when recalling how her mother irritated her at times” (p. 31). Rando’s work leaves me with the sense that my intense feelings of guilt are a natural part of the grieving process and that they may not really be founded on anything substantial—that is, I may not actually have been as awful a daughter as I remember. It is reassuring to know that the guilt I feel now may, in fact, dissipate with time.

Rando’s work has also changed the way I understand grief as a researcher. Although Rando does not use relational dialectics theory as a way to understand grief, her work has helped me to see that the grieving process is often fraught with dialectical tensions. Other researchers (e.g., Golish & Powell, 2003; Toller, 2005) have used dialectical theory to examine the communication of those who have lost a loved one; however, Rando’s work has led me to conclude that perhaps managing dialectical tensions and contradictory emotions are an intrinsic part of the grieving process. Take for example Rando’s overview of Lindemann’s (1944) *grief work*. According to Lindemann, the first basic task of grief is to “emancipat[e] from the bondage of the deceased” (p. 18). When describing this task, Rando uses the metaphor of “two hands clasped together with intertwined

fingers” (p. 18). She says that when two people love each other, they are intertwined emotionally; thus, when one person dies, the other must withdraw the emotional energy invested in the deceased and relinquish attachments to that person in order to develop new ones. This, however, does not mean the loved one is forgotten; the emotional investment and attachment to the loved one is altered, but the relationship “still exists in a very special way in the heart and mind of the griever” (p. 19). Rando’s metaphor instills in the reader the image of releasing or “letting go” of the loved one’s hand—a necessary step in the grieving process. However, as Rando mentions later, despite a cognitive recognition that they must let go of the person who has died, in some cases griever will experience an urge to “search for” or “recover” their loved one and may become preoccupied with thoughts of the lost person and the events surrounding the death. It seems, then, that as griever learn to release their attachment so that they may be “free to someday clasp another hand” (p. 19), they may experience a tension between their rational understanding that they must “let go” of their loved one and their emotional desire to desperately “hold on” to that person. Consequently, griever may find themselves communicatively managing this tension with those around them so as not to appear to others that they are maladaptively adjusting to their loss or maintaining an unhealthy attachment to the deceased.

The notion of releasing attachments is also reminiscent of the dialectical tension between independence and dependence. Some researchers suggest that once a person in mourning has intellectually and emotionally accepted the loss, he or she must then assume a new identity (Parkes and Weiss, 1983; Rando, 1984).

The griever must learn to live in a world in which the loved one is physically absent. It may be (and certainly has been for me) that one would have a particularly difficult time adjusting to a life without a loved one if he or she had been greatly dependent upon the loved one before the death, as daughters often are with their mothers. As I learn to live without my mother, I am trying to discover who I am outside of my role as my mother's caregiver. Although I am relieved to be free from the constant anxiety that comes with caring for someone who is slowly dying, there is part of me that would give anything to have it back. I was so very dependent on her for my sense of purpose and self-worth that I am now struggling to discover who I am apart from her.

Likewise, as I assume some of my mother's previous responsibilities, I am reminded of how much I depended on her, even while she was very sick. Making plans for Thanksgiving this year, sending birthday cards to my mother's siblings, and finally learning how to thread a sewing machine all served as small, painful reminders that my mother is really gone. It may be that doing such things is simply part of becoming an adult, yet when I find myself assuming a role that had once been my mother's, I cannot help but wish she were around to take care of things—not because I do not want to do them myself, but because I so desperately want to have a mother to depend on. Learning to adjust to a new marriage, a new house, a new “grown up” life is a challenge in and of itself—doing so while grieving my mother's death and figuring out who I am without her can be a bit overwhelming at times.

Considering the fact that most people who lose a loved one must negotiate a new identity after their loss and explore new life options now available to them (Rando, 1984), and considering that emerging adulthood is often a time of self-discovery and identity formation, it may be the case that emerging adults experience grief differently than do those at other stages in the life span. Individuals often experience many changes during emerging adulthood (e.g., moving away from home, exploring career paths, choosing a life partner, etc.); thus, attempting to adjust to the loss of a parent may feel overwhelming during a time in their lives already marked by significant transition. For example, one caregiver from the second phase of the study stated, “[N]ow I find myself—no longer a caregiver—with a confused identity (what do I do now? I’m no longer defined by my family) and starting out in the working world as others in their early twenties” (10a). Along with the difficulty of negotiating a new identity apart from their parent during a time already marked by identity exploration, emerging adults who are grieving a loss may experience a considerable amount of guilt for having sought independence from their parent during their time of self-discovery. Because very little research exists that examines the grieving process as it relates to emerging adults specifically, it is important that more scholarship be focused in this area.

Admittedly, doing this research was emotionally challenging, sometimes frightening, yet very healing for me personally. This, however, should not invalidate my findings. Because the qualitative methodologies presented in this work, especially autoethnography, are often criticized for being subjective and

“self-indulgent” (Ellingson, 2005), I am well aware that some may consider this research to be “too personal” or “too emotional.” I, however, strongly believe that scholarly research can be both evocatively expressive and academically rigorous. My findings—though they are not without limitations—provide valuable insight into the experience of caring for a terminally-ill parent during emerging adulthood and contribute to existing research in family communication, caregiving, and oncology care.

Researchers often forget that the social sciences are just that—social. Heidegger (1927/1965) reminds us that we are human beings—not things—who live in a shared world, a world that is made up of shared human experiences, such as death and grief. Thus, research that draws upon authentic, lived experience and human emotion warrants a respected position in academia.

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